

DOCTOR OF PHILOSOPHY

The Illusion of Inclusion: How Parents of Children with Dyslexia Perceive, Understand and Enact Inclusion

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The Illusion of Inclusion: How Parents of Children with Dyslexia Perceive, Understand and Enact Inclusion

By

Angela Thompson

PhD

May 2021

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Abstract

Pupils with dyslexia-SpLD difficulties on average significantly underperform relative to pupils without additional learning needs. This has been a historical pattern generating lifetime consequences for children's and adults' life chances and wellbeing. The current research explored the drivers of this inequality within the education system through examining the research question **'In what ways do parents of children with dyslexia-SpLD perceive, understand, and enact inclusion'**. Children with dyslexia-SpLD have a right to universal education and inclusion in mainstream schools. The study highlights the nature of inclusion as understood differently by parents and teachers, the difference has importance, in how the child and their family experience education, and how they navigate the educational system.

A 4-year qualitative longitudinal inquiry, using novel methodology of case study and critical realism engaged 72 participants (36 interview and 36 survey) through snowball sampling across two phases. Data were assembled into 2 multilevel case studies: a) parents of children with literacy difficulties, both primary and secondary age b) mainstream school staff, both primary and secondary. Analysis utilised a mixed strategy of hand and Nvivo coding. Data was processed, using Braun and Clarke's thematic analysis strategy within the context of a critical realism stance. This identified 5 innovative themes and 30 sub themes; with between 1,808 to 10,544 units of meaning coded.

A new construct of the structure of education (the Arc) from a child position was developed describing the structural architecture of education and the pathways of interaction, enabling explanatory frameworks of how disabling environments were constructed or challenged for children with dyslexia-SpLD. Novel contributions included that contrasting with typically developing peers, children with dyslexia-SpLD had uneven access to education or inclusion, and that happenchance played an outsized role in whether a child secured basic education.

A novel spectrum of 3 levels of disruption linked with dyslexia-SpLD development identified as Micro, Meso and Macro, related to different levels of discontinuity- disjuncture. These impacted on education access and psychological, social, and emotional distress. Disruption engendered variable damage to both the child and their family. In part some of the disruption was precipitated by structural features in the Arc of Education, but also included poor knowledge by both parents and school staff of what constituted the developmental profile of dyslexia-SpLD; the need to act early on visibility of dyslexia-SpLD; how small differences could have large impacts; and the legal framework, including rights and responsibility within it.

Explored in the study were how children with literacy difficulties operated closer to the edge of failure, and how the 3 novel different forms of agency: Compliant, Subversive, and Forthright were operated to limit damage or constrain features precipitated within the Arc of Education. These were used by parents as well as some school staff to mediate forms of inclusion. The study concludes by considering how inclusion itself can be enabling or disabling for different individuals, and how parents can influence forms of inclusion in practice, through addressing failures of service by direct and indirect means. Implications for mainstream education are highlighted, particularly the importance of child voice and epistemic injustice towards parents in negating visibility and knowledge. Recommendations for future development work are made.

Acknowledgements

To

Ian, Henry and Edwin

This is not a document I expected to write, or an award I thought I would be a candidate for 10 years ago. I was then an Open University student and the first tutor who mentored me Rob Wilde (RIP), former head of Department of Psychology at Coventry University, encouraged and chivvied me along, putting me on the path to this work. Module by module with thanks to Sue Nieland and Liz Blagrove, two other supportive and encouraging tutors, a psychology degree was constructed. One of the authors for the Developmental Psychology (ED209) module I had completed for Open University in 2009 was Clare Wood, and she too encouraged, and told me to come back with my results, and then offered me a golden opportunity to do a PhD and to fashion the project myself with funding. That this work exists was down to both Rob and Clare's optimism and the opportunities created for me, those that encouraged me; combined with an open exam question for that Developmental Psychology module, which was in effect "How does theory, research and practice link in the field of dyslexia?" My debt of thanks to all is heartfelt.

The work of a PhD is long and hard, and that was just for my husband, who read, coached me in writing and clarity of expression, and corrected all my essays through the Open University and then PhD work. Ian was as committed to this project and seeing the success of it all the way through, he debated points, made good suggestions, and who in the tough times kept me smiling, laughing, and pushing forward. He is my North Star and great love. To you this work is dedicated Ian. Whatever good may come from this work, will be down to you having provided sustained support to ensure it was completed.

So too to my amazing sons Henry and Edwin, who's capacity to be the best they can be, is a daily inspiration to me and a reason to complete the work. May you shine on. To my parents Sheila and Peter, thank you so much for all you have done for me and my family, your deep love for us all is woven though our lives. To my Mother-in-Law Jean who sadly died in 2020, and Father-in-law Keith, your encouragement and enthusiasm for our busy lives, success and support have been so appreciated. There are also friends who have played such important roles in providing the moments of help when needed and who celebrated achievements.

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To the participants: I hope in this work I have honoured your stories your knowledge and experiences and that you will find an honest account of the world you navigated as participants, parents, and school staff.

A special thanks go to Ben Meehan from QDA Training for his technical support across the project. When I started the University did not support NVivo which I had identified would be an important tool for me. Ben has gone well beyond the essential into the exceptional of technical support, as I tried to marshal a mountain of data to tell the story of the parents and teachers and maintain rigour. Also, to David Johnson for help in modelling the Arc of Education graphic in 3D. The other unsung heroes are the library staff and service, who dug in deep and negotiated access to sources, who secured other versions of papers the electronic service could not provide and were just very helpful.

And to the amazing (or should that be superlative) supervisory team. Professor Julia Carroll, Professor Clare Wood, Dr Sarah Critten and Dr Simon Goodman. Each of whom had to

sit in the hot seat as Director of Studies as the winds of change blew through education. All who were committed to the project and saw it through to the end, given its length not an insubstantial contribution of fidelity. The team worked to provide the critical friend role to challenge and support. They came from different perspectives and so they were an important bulwark against different forms of bias including my own. Supervision was the place the work could be discussed and challenged; and for the methodology that was important. A truly outsized thanks go to Professor Julia Carroll who with the last breeze in the system scooped up the project and with an unusual level of commitment ensured it got over the line. This was a significant project, it was not easy to navigate, and Julia, a late addition ostensibly as a technical advisor, took the whole thing on. To all, my appreciation and gratitude is sincere; any errors, mistakes and misunderstandings are mine.

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Chapter 1: Introduction

The Challenge
by
H Thompson (April 2016 age 15)

*Aarrrrr my hand and wrist are so soore
The unsertanty of werther iv spelled a word right
I don't know how to start a sentens
Imm getting more and more upset and frustrated and so I cant consenstrate which gets me
more upset and frustrated
Got nose bleed from stress and I now have blotches of scarlet over my page
When I try to re read my work a can read it because my hand-wrighting is so bad
When I am able to desifer the strange marking that is my work, it dosent make sense
because of my thought proses so its been written in a werd way
All the stress and anger have bilt up and I run out of the room snapping my pencil
and throwing it at the annoying girl who ceaps singing ABBA's houny houny houny.
I then run to the bathroom in which I lock myself in one of the cubials
© Henry Thompson 2016*

The above piece was independently composed by my eldest son in response to the English task when he was 15, these were his notes. Henry could not think of a challenge he had overcome, which was the given topic, until he came to realise that he lived challenge every day. Despite his very evident limitations in literacy he was still experiencing, his English skills had significantly improved from his starting place. So, he wrote about his feeling of writing in primary school. It is his, a first person un-mediated insider account. It demonstrated powerfully how literacy and the tasks of learning are, for children like Henry, not the decontextualized academic tasks of skills and practice populating the academic literature; or mostly experienced by typically developing peers. Instead, they are loaded with psychological, physiological and social stress, even for the most basic of class tasks. This is one account, one with personal impact, but not unique, of what having dyslexia or as it is sometimes referenced Specific Learning Difficulties (SpLD), means in the real word and in lived experience.

The problems of dyslexia, having dyslexia, or being dyslexic are very different depending upon what position the problem is viewed from. Parent's accounts and knowledge

have had little privilege in the academic literature, and limited presence in the school accounts, despite the common narrative in the public domain from parents, over many decades, of unsatisfactory education. Academic and educational professional work has made gains in many areas of knowledge and relative improvements have been achieved. Much work has been done to inform and apply the tried and tested ways of teaching most likely to optimise a child's capacity for acquiring literacy skills. However, the decontextualized nature of this information has meant that the main focus for parents, that of their child's distress, has had exceptionally limited exposure in the literature. For a sizable section of children who have a profile that includes dyslexia or the broader construct of specific learning difficulties the work has not fundamentally changed their outcomes.

It was reasonable then to address this undervalued gap in the academic knowledge base, and ask a group poorly represented in the literature, parents; about what they knew and understood and observed about their child in education. It was important to understand, rather than assume how they experienced the system. To see if they had useful perceptions that could identify missing insights. Ones that could help develop the system's responses to this group of children, in a more fair and equitable way than had been and was currently being delivered.

To do this it was necessary for me to identify what was known, how it was known and the limitations of the knowledge; that work has informed the literature review (chapter 2). The review took in a wide range of topics linked to the broad areas of dyslexia (and as it related too specific learning difficulties - SpLD), Special Educational Needs (SEN) and was then narrowed down to topics of dyslexia-SpLD, inclusion, the history of educational legal system, methods of inquiry and parents. Key points relevant to the research question are presented in the literature review. The evaluation also highlighted how methodological issues had acted as a constraint on inquiry and findings, such that natural gaps occurred in the literature. This led to

further examination of new ways of research investigation. The details of how and why the study was configured the way it was, how it was operationalised, who it involved, and in what way; are in the chapter 3 (Methodology). In the figure below the simplified order in which themes were explored across the study are illustrated. It started with what was observed and seen, then the factors that shaped what were seen were explored, and finally the material was consolidated into two key themes the Arc of Education and Illusion of Inclusion.

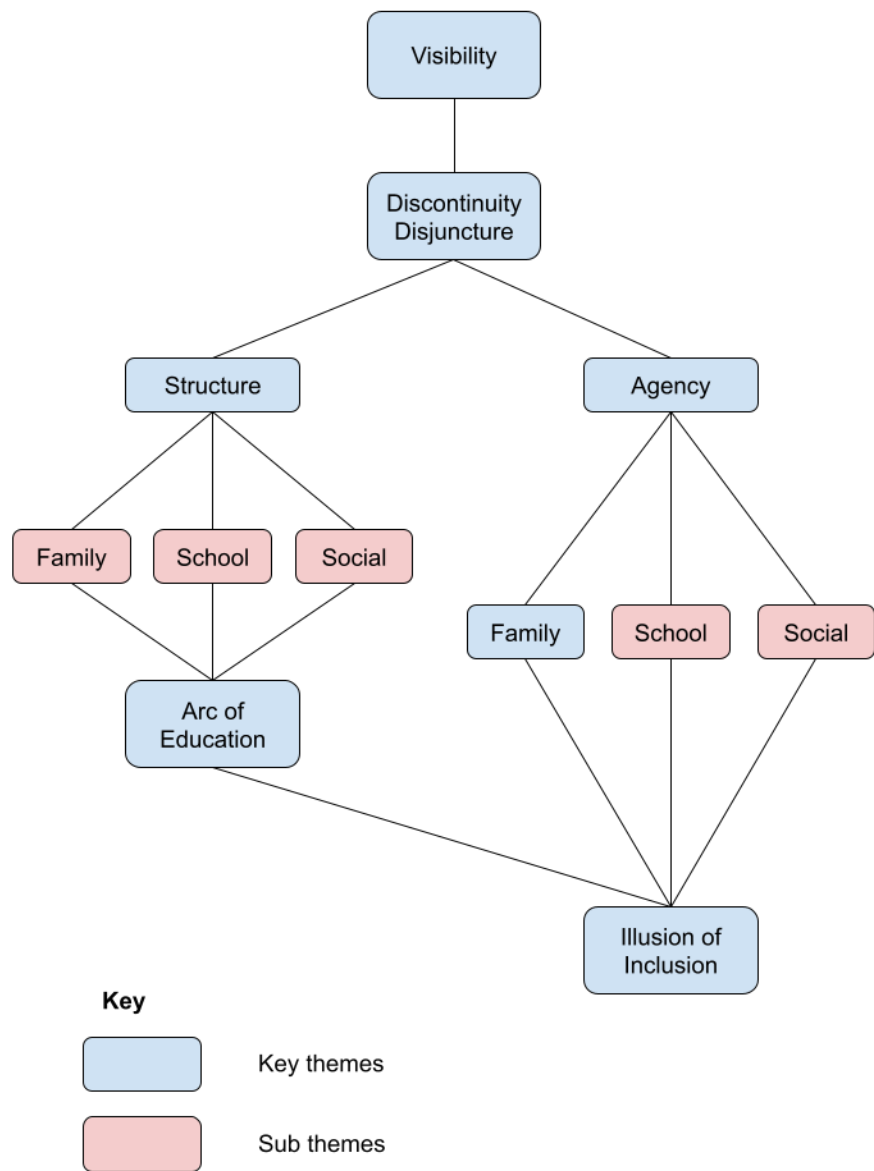


Figure 1 Simplified order in which themes were explored across the study

The principal theme identified was of 'visibility'. Visibility is used as a broad term to describe the process of observation and interpretation; what people see, hear, sense, and recognise as relevant information. It is a term that covers the very small almost invisible differences that can be recognised, right to the perceptions around system features and impact. It also covers the recognition of different forms of knowledge and authority. One of the tasks was to make visible the structure of education at the school level and how it was located by the system. The Arc of Education (chapter 4) was derived from examination of descriptions provided from different participants' perspectives of what has happened to them and why and how they understood the events. The accounts collectively created and occupied contested space, which allowed for an understanding the intersections between competing drivers. The Arc of Education is presented before the main results chapters to help to orientate the reader towards the data and the key themes found within.

The three principal results chapters have a mixed data and discussion profile. The section starts with the main overarching theme of Visibility (chapter 5). This is a descriptive chapter of findings which looked at what visibility was from different levels and locations of the education system, contrasting that with accounts of parents and the literature. Dyslexia or SpLD is a difficulty that is often thought of as invisible or hidden, with relatively poor or intermittent recognition. The theme of visibility examines the ways dyslexia or SpLD becomes visible (or not) in an education setting. The analysis demonstrated that the participants were recounting a consistent story with that from other eras and territories. Substantively this has remained an unchanging story but was extended by elevating the description to consider the inherent conflicts and implications of structure (in the form of the Arc) and agency (how people operated around the Arc). The next two chapters address, through parent and teacher accounts, how a child functions within a structure and system. Chapter 6 *The significance of Discontinuity and Disjuncture in the practice of inclusive education* (discontinuity-disjuncture) explored the patterns found in the data around different types of disruptions in education,

with three identifiable levels that played a role in shaping the learning, psychological and emotional experiences within education. The type and nature of disruptions carried beyond the geographical boundary of the school and into the home and community. Chapter 7 *Parental and Teacher Agency: A New Construction* (Agency) picks up the threads from chapter 6 and examines the core issue of parental and school agency. What parents did in response to what they observed. It identified how their actions as forms of agency had different forms of visibility to the community and the school and the impact of that form of visibility in mediating children's outcomes. Three forms of agency were identified but one of them had low visibility to the school. It was however important as a way of parents seeking to support their child and facilitate their notion of inclusion. In this chapter there are some links with the literature, but again the focus was on the data and analysis.

The results chapters and the literature are then drawn together in an overarching results and discussion chapter, chapter 8 *General Discussion - The Illusion of Inclusion* (Illusion of inclusion). This draws on the data and analysis advanced in chapters 5 to 7 within the context of the literature and focuses on two points. The first is for how inclusion was formulated at the individual level. How the parents seek to represent and respond to the child voice, and the importance of both the child's voice, and the parent's voice. The latter as a courier for their child's voice and experience. The second point was the identification of the pathways of discontinuity and agency. These were identified using a critical realist approach to thematic analysis. They illustrate potential mechanisms for how some of the contingent damage sustained by the child and family could be mitigated.

The final chapter is the conclusion (chapter 9 *Key findings, conclusion and reflection*) is a brief overview and reflexive section, with some pointers for future development.

Chapter 2: Literature Review

Introduction

This literature review covers four key topics that are central to this study, they are the nature of constructs and knowledge of: Dyslexia, Education with a focus on the legal framing of Special Educational needs, Inclusion, and Parents. For the latter, the focus was on being parents to a child with dyslexia. The chapter draws this together by considering the limitations of current knowledge, how this is shaped in part by the methods of inquiry and why an alternative strategy was needed to ask different types of question. It summarises the landscape and proposes a research question for investigation which the study then addresses.

Dyslexia

Literacy broadly, and specifically relating to the ability to understand and produce written language is an important social-cultural tool that as e.g. Perry (2012, p. 324) identifies, allows displaced personal connectivity. Both anchoring the individual and their social world into and through their own and collective history, as well as enabling the capacity to create future social history for self and others. Literacy goes beyond utility decoding reading and encoding writing. Its importance as a tool lies not just in the way social structures and communications are navigated in the here and now, but also in the expression of personal agency expressed across time (Perry, 2012). Literacy allows us to move beyond the direct but transitory interpersonal communication using oral voice, and to access and leave markers of the person beyond the temporary as part of wider human development (Freire, 1983). Within that context, a systematic difference in the capacity to become literate has broader impacts, such as the capacity to contribute to society and to participate in it.

Locating dyslexia in the wider context of literacy

One form of restriction to acquire literacy is termed dyslexia, which in a 2020 radio interview Snowling described as a “difficulty reaching the level of fluency in reading and

spelling that we would expect in an adult” (Withers, 2020, 4:59). In many respects dyslexia in common parlance has become the default shorthand description for the “minority group” (Macdonald, 2019, p. 18) who are identified when other accounts to explain their difficulties in acquiring literacy skills are not available. The unexpected nature of the difficulty, the diversity in strengths and difficulties experienced by the learner as well as the “unconventional intellect when confronted with problems and situations” (Macdonald, 2019, p. 18) are features in the common narrative associated with the dyslexic profile. However, reading difficulties can occur for reasons other than dyslexia. For instance, there is a difference between comprehension of text due to word level difficulties and vocabulary difficulties (Spencer et al., 2014) and so clarity regarding the source of difficulty is important for effective intervention.

In contrast some constructions of dyslexia draw upon a positive representation such as innovation and entrepreneurship (Made by Dyslexia, 2021) as well as recognition of common forms of difficulty. There is controversy about how dyslexia should be recognised and diagnosed and this has been well documented (Evans, 2020; Kirby, 2020a; Protopapas, 2019; Snowling et al., 2020), and this debate has persisted in its current form and been ongoing since the Tizard Committee report in 1972, who rehearsed the same critiques and counter challenges (Alexander, 1972). The debate is nested within and links to disputed notions of what constitutes special needs (Reindal, 2010) or differences (Macdonald, 2019).

Sociological and research constructions of dyslexia

Inquiry around dyslexia has shifted focus over the last 30 years, with ontological aspects shifting gradually from the decontextualized individual to the system. Macdonald (2019) explored the 6 ways different constructions of dyslexia that have been used in UK research; noting they ranged from “disordered to diverse” (Macdonald, 2019, p. 1) from a narrow biological to biopsychosocial to social to part of natural diversity. Each model takes a different ontological and epistemological stance and so considers the problem or difference from quite different perspectives which also suggests different forms of resolution. Each of

those six models: 1) biomedical, 2) biopsychosocial, 3) social model (disabling barriers) 4) critical realist, 5) post-structuralist which included the affirmation model, and 6) neurodiversity (Macdonald, 2019, p. 1), offers a narrative about how the profile of difference called dyslexia is situated and how the life stories and trajectories can be enhanced.

Nevertheless, for around 4-8% of children (Macdonald, 2019, p. 7) there is a disjuncture between how a child and young person learns and engages with a key social tool, literacy, that mediates life chances, and their capacity to acquire those tools, which leave children, later adults, without key social tools and associated autonomy. Some models focus upon defects within the person - those models have been identified as a psycho-medical. Alternatively, it has been conceptualised through a social-cultural experience, where disability is constructed; insomuch that society does not respect differences and offer ways to accommodate. As Macdonald (2019) notes, the phenomena of dyslexia has biological, psychological and social features and there is no sense in Macdonald's work that any one of those features has priority in the expression of the profile.

Dyslexia as a developmental difficulty or disability

Developmental research takes as a starting position that there are interactions between biological and environmental influences (Diamond, 2009) (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Evans, 2000) and at varying levels this has been acknowledged in research in the examples cited above and in the literature review examining theoretical, and practice implications (cf. Frith, 1999). Initially the focus was on identifying singular deficit explanatory frameworks but then moved to multiple deficits (Pennington et al., 2012). However, in a prospective study looking at which factors predicted dyslexia for prereaders, on follow up it was identified there was a mixed profile of potential causal features.

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Figure 2 The frequency of poor reading for a given a pattern of deficits Taken from Carroll et al (2016, p.755.) 4% of poor readers did not show any of the three areas of deficit, but 75% of poor readers showed all three areas.

This important study by Carroll et al. (2016) illuminated two core findings, the first was:

“[examination of] which of the three different schools the child attended. Only this predictor explained significant variance, showing that some variation is due to school or class level factors”

(Carroll et al., 2016, p. 754)

Secondly that there was no one factor that predicted over 50% of variance of poor reading. Across the findings were recognition of how the factor of which school a child attends (recognising that contains multiple sources of variance) plays a central role in the development or otherwise of poor reading, and how multiple factors within the child combine to create cumulative risk of poor reading independent of setting. The risk can be at individual level, for instance heritability factors such as family risk of dyslexia (where a first degree relative has dyslexia or meets the criteria for diagnosis of it), were found to be a strong predictor of reading outcome at age 6 (Thompson et al., 2015), but it was also found in a review by Snowling and Hulme (2020) that a good quality educational environment could go some way to mitigating that kind of family risk , while a poor quality educational environment could exacerbate it.

Carroll (2020) noted in her review, the consensus is now towards the idea of multiple factor models (McGrath et al., 2020), where typically there is cumulative risk rather than a

singular causal feature. Further within this framing McGrath et al. (2020) argued there are protective factors, that mitigate those most at risk; along with promotive ones, which universally help all individuals. However, while there was evidence for the latter, there is a lack of substantial work examining protective factors. This is consistent with the longitudinal study of 53 at risk children/families across 10-year span for children up to age of 13 by Muter and Snowling (2009) and the later study examining the relationship between home literacy environment and later reading difficulties, which again showed the impact of some protective factors for students located in settings of the poor Social and Economic Status (SES) (Hamilton et al., 2016). At the other end of the education spectrum a recent in depth case study by Niolaki et al. (2020) of three students in higher education with different personal and demographic profiles who presented with literacy difficulties but not a diagnosis of dyslexia were compared to a student without literacy difficulties. The case study uncovered the detail missing in quantitative studies of a multiplicity of different at-risk factors that shaped or supported the individual profile, again supporting the proposition of the profile drawing from a complex array of multiple risk factors and demonstrating the benefit of using case study as research approach to make explicit how decontextualized factors can present in real life

The historical context of dyslexia and its representations in research

Dyslexia, with its origins dating back over 100 years (Kirby, 2018), first presented as a medical conundrum and has remained so with a pattern of selective disruptive features, ones which lacked easy explanation. It has continued to present as a puzzle of differences, for which the critical feature is disruption in ability to acquire and use skills for the socio-cultural tool of writing-based literacy, and further, that this was unexpected given the profile of skills and attributes the child displayed in other areas. Kirby (2018; 2019, 2020a, 2020b) has provided a comprehensive historical account of the background and emergence of recognition of dyslexia leading up to the Rose Report on Dyslexia (2009) and the persistent contested space around it.

Snowling has recently described dyslexia as “being multifaceted” and outlined both the narrow and wider definitions of the profile (Snowling et al., 2020). It was associated with stigma as lack of literacy skills was linked to intellectual disability and to the term stupid. Many of the hostile responses towards dyslexia have drawn on these motifs (Kirby, 2020a, 2020b). However, in more recent years there have been concerted efforts to challenge negative perceptions linked to both the difficulty in learning to read and spell and write, or for those claiming the label of dyslexia; through a focus on neurodiverse profiles of strengths and well as limitations (Macdonald, 2019). Dyslexia also has positive representations in popular culture; for instance as Percy Jackson, dyslexic eponymous hero of a range of popular children’s fiction by Rick Riordan (Kirby, 2019, 2020a). While the dominant narrative in research has been about the problems linked with of dyslexia reflected in Macdonald’s (2019) review, conversely as he recognises others have celebrated it as a positive form of diversity that provides enhancements or ‘gifts’ (Made by Dyslexia, 2021; Sabin, 2020).

Dyslexia interventions: those that work and their limitations

Mechanisms for evidenced-based means of addressing dyslexic difficulties

Using a biological-cognitive model which examines deficits in specific areas of processing and with respect to English language, there is good evidence of approaches that improve specific literacy outcomes in dyslexia (Snowling & Hulme, 2012; Tanner et al., 2011; Torgesen et al., 2001; Vaughn et al., 2008; Vellutino et al., 2006; Williams et al., 2016). These approaches centre on close examination of detail from assessment of progress, structured mechanisms for learning language, and grapheme-phoneme correspondence, and practice for fluency. The dominant model focuses upon phonological processing. It seeks to build through structured exposure effective mental representations of the phoneme-grapheme links that underpin spelling and reading in English; as described in the report led by Rose (2009).

The biological-cognitive stance conceptualises dyslexia as a within person deficit and difference, related to information processing. Those within-person differences can be mediated by contextual factors for example home literacy environment, family involvement in and level of education, health, type and nature of school support, age of first diagnosis and ability to secure diagnosis, presence of other learning differences as captured by Snowling et al. (2007), Muter and Snowling (2009) and Riddick (2010). A significant portion of the literature and debate around ‘fixing the child’ (Macdonald, 2019), was how strategies of exposure to stimuli and reinforcement of the desired learning were to be implemented, and at what stage of education (cf. Brooks, 2016; Fuchs & Fuchs, 2006; McMaster et al., 2005). In that respect the main thrust of learning had a behavioural psychology orientation (cf. Joseph et al., 2016; Rupley et al., 2009). It is worth noting that learning under these behavioural reinforcement conditions is variable, and such strategies often require continued practice (or maintenance) if the learning is not to fade or be extinguished (Sauce & Matzel, 2013).

Key issues around learning to read for typically developing pupils

This observation draws down from the contentious debate which was not anchored in dyslexia but for typically developing readers and sometimes referenced as the ‘reading wars’. This was between proponents of ‘whole language’ (which focused on child self-motivation) and ‘synthetic phonics’ (which focused on the decoding skills) advocates. Interestingly both sides of the debate (Smith, 2012, pp. 312-314) and most recently in the example of the government’s reading framework document (Department for Education, 2021), dismissed or ignored the construct of dyslexia. Both sides assumed the position was that all that needed to happen was application of their preferred strategy. The evidence strongly suggests that decoding and the teaching of it is central to the skill of reading (Nation, 2019), but examining the literature and government data it is also the case that 10 years of a policy of sustained systematic phonics teaching in mainstream English schools (as well as the devolved nations and internationally) has not caused dyslexia to evaporate away. Learning to read and write is

seemingly not just a skill of reproduction but as tool of personal agency and engagement, this context even for typically developing children moves beyond the abstracted cognitive process into the whole person experience.

Cremin et al. (2009) demonstrated that teachers needed to also be taught how to teach the skill of reading for pleasure. This may appear at first glance odd, but a sophisticated skill performed expertly, which reading would be a case for teachers, would be so automated that without help it may be difficult for them individually to deconstruct to earlier less skilled levels. This is also a salient point of reflection for understanding how for some adults could fail to fully appreciate the challenges faced by a child, where learning decoding is not occurring along a natural arc. Areas of support explored in Cremin's study (2009) and later work (see for example reading for pleasure website with Open University <https://ourfp.org/>) were about developing reflective practice as 'teachers of reading' and 'reading teacher', and knowledge of children's literature and building reading communities. Finally, more recent work by Vousden et al. (2021) demonstrated through a well-structured and controlled study how the explicit teaching of phonics as well as the explicit teaching of language and comprehension in phased parallel manner had significant positive impact in later national assessments of literacy.

Interventions for dyslexia

Interventions for dyslexia, have principally but not exclusively (e.g. Nicolson et al., 2001, focused upon automaticity and cerebella function) focused upon deficits at the word level and its sub components (e.g. Ritchey & Goeke, 2006; van Rijthoven et al., 2021). Such work draws upon a relatively narrow area of psychological theory and research examining the information processing characteristics and stimulus-response features of language processing and acquisition. Intervention in the best cases used such evidence, converting it to a structured progressive programme of study for a child or adult to acquire core literacy knowledge (see examples at: Dyslexia SpLD Trust; Rose, 2009).

The efficacy of such intervention has remained contested. Findings from two different strands of intervention demonstrate that both approaches which differ in their focus have limitations. This is important to recognise as claims of superiority of a strategy have not been supported by the evidence of universal application and success. There is not one strategy that works for all children, and that has been problematic in delivering effective intervention on a mass scale. Ritchey and Goeke (2006) reviewed 10 studies covering 961 participants examining the perceived efficacy of a multisensory structured approach using strategies consistent from the Orton-Gillingham multimodal model for learning to read and spell and found a mixed picture with around 6 studies finding some benefit at the group level, but with variability.

An alternative strategy using approaches consistent with direct and explicit instruction (Rupley et al., 2009). van Rijthoven et al. (2021) conducted a study on 54 children who were in the bottom 10% of their peer group for literacy skills after they had already had 1.5 years of intervention. Using a phonics through spelling programme, they again found a mixed picture of individual irregularity and resistance to intervention. The latter study had less than half of the participants moving out the bottom 10% level. What these two sample studies suggest is that the strategy alone appears to be insufficient and that would point in the direction of the profile of individual differences, pupil teacher alliance and the context in which intervention is delivered.

One of the novel findings from the van Rijthoven et al. (2021) study was that while the pre-intervention cognitive testing did not reliably indicate who would respond well to intervention given participants were all in the bottom 10% at the start and had already had 1.5 years of intervention, the post-intervention testing of phonological processing did, this added an additional dimension to response to intervention strategy (Fuchs & Fuchs, 2006). However, both studies taken in comparison illustrated that the two most common strategies used to

address dyslexia, multisensory and direct instruction, were both found wanting, with mixed picture of perceived success.

The research overall therefore suggests that teaching strategies that focus on phonological processing and phoneme-grapheme correspondences; known areas of weakness for dyslexia (Snowling, 1980; M. J. Snowling, 2013), have a mixed response at the group as well as individual level, working for some, and could specifically produce positive and strong effects for individuals, but not consistently for all. However, these were studies that focused on a particular form of intervention in relation to reading and spelling. Other dimensions such as psychological, social, or wider access to education were not part of the consideration, either as benefits or costs. Consequently, they provided a narrow view of the selected strategies' contribution. That was a point reflected by Macdonald's (2019) view of the multiple constructs of dyslexia in research and the limitations of narrow biological conceptualisation.

Intervention resistance: when intervention fails to make meaningful change

There is also evidence that interventions do not always work in the way they need to (McMaster et al., 2005; Torgesen, 2000) and that applies to both reading and spelling (Galuschka et al., 2020; van Rijthoven et al., 2021) where the observation of "treatment resister" or non-responder (Torgesen, 2000, p. 55) profiles is a persistent phenomenon of a sub-set of children who do not respond as expected to tested and evaluated strategies. For instance van Rijthoven et al. (2021) examining a joint spelling and reading intervention in Dutch children found only 49% of children were raised out of the bottom 10% for spelling and the figure was less for reading. However, the idea that there is a treatment, thus expressly calling down the medical aspects of the model, is illustrative of the limitations of focusing upon a particular biological/cognitive formulation of dyslexia in which causality is relatively impervious to context.

Indeed the implication in Galuschka et al. (2020) systematic review and meta-analysis that investigated the efficacy of spelling interventions and concluded that the evidence base was poorly disseminated to educators. Further that there may be poor fidelity to the methods, strategies and to the contextual systems used within the research that had produced the strongest results. For instance, the study found individual teaching was most effective and yet school staff had reliance on systems that produce the weakest results -class teaching and learning list of words. The lack of application of the research base into education in England was also a finding of a rapid review of evidence related to interventions for SEND (Carroll et al., 2017).

Instead, the cumulative evidence points in the direction that dyslexia can result from diverse forms of difference suggesting a range of interventions may be required. Some candidates anchoring interventions such as phonological processing having a stronger role or presence in research (Pugh & Verhoeven, 2018). Other interventions have been found to have poor evidence base for instance Bull (2009) explored how parents were using alternative therapies such as nutritional supplement, homeopathy, and osteopathy that would be unlikely to remediate the underlying mechanisms leading to dyslexia presentation. However, a singular within child and phonological based stance also does not recognise that there are changing needs of support and intervention across time and development and this was captured in a qualitative study of Higher Education (HE) students providing accounts of the school years experiences (Gibson & Kendall, 2010).

Singular and probabilistic risk, the role of language mediating a hidden disability

However, while Carroll et al. (2016) identified for poor readers there was a complexity of profiles, and this fitted with the notion of probabilistic risk (Pennington et al., 2012). That was best understood as cumulative loading of risk that raised the threshold of personal factors to the point, they became apparent as dyslexia. The risk was also offset by protective factors, so that it was the interactions of a range of risks that lay behind the empirical presentation.

This also accords with Macdonald's (2019) notions of the separation of impairment and disability for dyslexia. This does not preclude there can be cases of pure singular deficit. For instance, it was found from an important case study that for a bilingual person it was possible to be dyslexic in one language, English, but not in another, Japanese (Wydell & Butterworth, 1999) a case of double dissociation demonstrating the specific contributory role of phonological processing in a form of dyslexia. This case also demonstrates even in models of probabilistic risk that it is possible to have a singular causality linked to a specific language representation. Such complexity has made clarity around the profile challenging.

The other implicit finding from the Wydell and Butterworth (1999) study was the way the qualities of language were salient in the manifestation of dyslexia, confirming and illustrating its hidden disability qualities. This also extends to the degree of complexity within the language structure, in how consistent any orthographic representation is relative to the linked sound correspondence (referred to as its transparency). English is recognised as having poor transparency with orthographic representations having multiple sound links and the challenge and demands of acquiring it are therefore greater than others such as Greek (Diamanti et al., 2018). A natural extension of this finding is that local variation of language may also add levels of complexity and demands on learners who have increased risks when oral language may have relative variability, but the written language has relative stability. This is an area that has yet to be explored.

The differences in how mental representations of Japanese and English language are constructed; one using forms of pictograms and one alphabetic, also highlight how the learning process could mediate presentation of dyslexia. The focus for dyslexia intervention has been on direct teaching of the alphabet and its principles using phonics teaching, which research suggests to be the most effective strategy (Rose, 2009). However a school in Lichfield has developed a means of teaching, drawing on visual imagery (icons) and morphology as an

alternative way of learning to read and write (Brown, 2020; Maple Hayes Hall School, 2020) drawing similarities with pictograms, with good outcomes relative to national data for those who had been consistently intervention resistant or non-responders with different 'standard' interventions. Across the accounts there is a range of evidence that a single descriptor of dyslexia based upon the causal mechanism lacks rigor at the general level. While common profiles and common forms of causality can be recognised, they are not definitive and nor is there a universal one size fits all intervention strategy.

Psychological co-morbidities and sequelae of dyslexia

Apart from the technicality of acquiring cultural tools, there are also multiple accounts of the psychological sequelae such as anxiety and the impact of gender bias linked as part of the response to difficulty (Carroll et al., 2005; Nicolson et al., 1999; Quinn & Wagner, 2013). The accounts suggest that literacy difficulties predispose children with risks for instance towards anxiety to development of full clinical profiles, and that the poor recognition of children in difficulty by school is likely to add to this generating psychological stress. Further, embedded expectations of presentation for instance male gender may lead to people overlooking the prevalence of difficulty in girls. This suggests that singular solutions such as a reading or spelling programme as isolated interventions fail to address the holistic experience of difference that extends beyond the boundaries of literacy and education and across the lifespan (Evans, 2020; Miles et al., 2006; Sandoval et al., 2021; Savage, 2004). There is also the matter of poor recognition of problems of literacy within school. Quinn and Wagner (2013) found that not only was there a failure to identify children with literacy difficulties but that it was gendered, with 1:4 boys being adequately identified with literacy difficulties but only 1:7 girls. Dyslexia also has poor visibility in some communities such as Afro-Caribbean and traveller heritage ones (Lindsay et al., 2006). Additionally profiles of mental health distress (Carroll et al., 2005) dyslexia and poor-quality inclusion have a recognisable long-term impact on health and wellbeing (Carawan et al., 2016; Deacon et al., 2020; S. Macdonald, 2009b).

The secondary effects of dyslexia/literacy difficulties including psychological and mental health have been described, and they present as something of a mixed picture with some authors not identifying needs (Humphrey & Symes, 2010), while others finding persistent evidence (Carroll et al., 2005; Dahle et al., 2011; Ingesson, 2007; Kalka & Lockiewicz, 2018; Leitão et al., 2017; Riddick, 2010). To date this aspect seems to have had little direct impact on practice. The tacit assumption has been that acquiring literacy skills will remove/reduce secondary impacts, but this may not be the case and there is currently not a sound explanation of how deficiencies in literacy skills linked to dyslexia cause or give rise to mental health difficulties.

Dyslexia across the communities

Dyslexia is overrepresented in particular groups including those in the justice systems, the unemployed and those in the armed forces, as illuminated by the work with voluntary bodies such as the Cascade Foundation (<https://www.thecascadefoundation.org>) who provided field support to vulnerable groups. They note that 80% of youth offenders have dyslexia along with 53% of prisoners, 55% of unemployed individuals, and 50% of Army veterans. The source of the figures is not fully disclosed but Loucks (2007) in a literature review for the Prison Reform Trust reports 'No one Knows' notes for the UK prisoners' profile was "30% dyslexia, though rates of serious deficits in literacy and numeracy in general reach up to 60%." (Loucks, 2007, p. 2). The general picture is of higher presentation of literacy difficulties/dyslexia in these populations than found in the general population. The findings are consistent with other forms of inquiry (for example: All-Party Parliamentary Group For Dyslexia and other SpLDs [APPG-Dyslexia & SpLD], 2019b). For the homeless populations the indications are those with dyslexia fare worse than other homeless peers with mental health issues and self-harming behaviours (Macdonald et al., 2016).

The focus on scientific forms of inquiry at the cognitive level has yielded valuable insights, however for the most part they are decontextualized. One of the rare forms of

contextualised research has been done by Niolaki et al. (2020); Niolaki et al. (2014) who has used in depth single or small group case study to explore how bilingual children with dyslexia using both transparent orthography (Greek) and obscured orthographies (English) respond to intervention. However apart from this limited work the dyslexia literature has not paid sufficient attention to the intersection of dual forms of disadvantage, such as structural ethno-cultural location, which positions a child and family with respect to visibility and access of opportunity intersecting with information processing differences such as dyslexia and how this impacts on access to education (Lindsay et al., 2006; Morgan et al., 2020).

There remains the challenge that even in research studies, the quality of outcome, regardless of strategy used, still has variability; in a way that is taxing for the child, its parent, teachers and policy makers. The next section will address the context of interventions.

Reframing Dyslexia, as Dyslexia-SpLD

The literature above alludes to contested position around definition of the term dyslexia that has been an ongoing unresolved issue for the field. As Kirby (2020a) has implicitly suggested, this arguably distracted progress in developing common understanding and recognition of the profile impacting on educational delivery. From a cognitive psychology-science research perspective, narrow definitions were important to securing reliable knowledge through research in the field of cognition. However, it became apparent that defining terms and limiting participants to a narrow group for research purposes had limited ecological validity. Application in the real world of education involves complexity as the norm, illuminated with the 10-year longitudinal study of children with heritable risk of dyslexia (Muter & Snowling, 2009) and case study by Niolaki et al. (2020).

The contested nature of dyslexia definitions has led to use of the alternative label 'specific learning difficulties' (SpLD); but as a term, that does not allude to strengths, only negatives ("difficulties"). The term SpLD directed attention to the observed and behavioural

element, rather than the theorised causality implicit in a discrete category (Snowling 2005). It allowed for a range of atypical development profiles to be collated together under a general term; difficulties with literacy (dyslexia), maths (dyscalculia), organisation and sequencing including movement (dyspraxia), were all SpLD (Snowling, 2005).

The assumption in SpLD as outlined by Snowling (2005) is both normative and of a discrepancy in some aspects of cognitive development, with marked departure from compatible progress in one or more areas of skills mastery, or function, relative to other areas of development. What the term did allow for was the complexity of a child's profile to be represented, recognising that specific learning difficulties could describe a multifaceted presentation where more than one identifiable form of difficulty could interface generating cumulative challenges for access to education.

However, two aspects were problematic in relation to this research. Its focus on learning could suggest that the problems were just about teaching the child effectively. The possible implications are that such difficulties evaporate if the issues with learning are resolved; for example, with skills teaching to meet an exam threshold, or use of technology, or if the teacher adapted delivery. This presents the profile as transitory and contextual, not recognising the problems had in many cases a deep constitutional origin rather than one of surface nature around learning. For example, Snowling and Melby-Lervåg (2016) who through a meta-analysis of longitudinal study identified language difference in future dyslexic children long before reading developed, demonstrated that pre-educational differences for those who developed literacy difficulties could be identified. Additionally, as has been described previously such differences persisted across the lifespan and were less circumscribed than the name 'specific' suggested. Secondly that the term itself lacked specificity, it covered a wide array of developmental differences and there was nothing that suggested in use of the term SpLD for an individual where the key significant difference of difficulty lay.

From a dyslexia perspective Nation's (2019) thoughtful and insightful reflective work using longitudinal study data to review the 'simple view of reading' illustrated how complex, overlapping and nuanced the initial 'simple view' was the model articulated by Gough and Tunmer in 1986 (Nation, 2019, pp. 48-49). It had posited that reading comprehension, the principal goal of reading, was the interaction between decoding and linguistic comprehension with deficits in one domain constraining the other. Dyslexia in the original framing occurred when there was relatively high linguistic comprehension and low decoding. Nation (2019) demonstrated that while the essence of the model held up, there was more complexity to it around language processing.

However, in the real world, as explored in the literature review, dyslexia is more than linguistic comprehension and decoding. As discussed in literature review children presented with a range of other differences around attention, memory, efficiencies of processing, sequencing, coordination, temporal sensitivity, as well as language (e.g. Snowling, 2005). Of lesser recognition but referenced in the literature, was the way in which the experience of learning to read could be psychologically corrosive and lead to longer term damage. This was exemplified by Johnson (1985) three case studies of adults with dyslexia, and later again with Deacon et al. (2020) larger case study, and how negative emotional experiences around learning to read shaped participants future lifeworld and response to literacy. In this respect the difficulties identified in learning to read and write became 'whole body' problems with longer term health implications.

It is for this reason that throughout the thesis from this point in the literature review onwards the term dyslexia-SpLD has been used as an ecological description a principal difficulty in literacy within the context that a child or adult may have other co-occurring difficulties. The exceptions to its conjoined use were if *someone had specifically used the term dyslexia or SpLD as part of their voice or research*, for instance English government data uses

the wider term SpLD, not dyslexia, dyscalculia, or dyspraxia, while other research specifically is anchored in the construct of dyslexia *in which case the term reflects either dyslexia or SpLD as originally used*. The term dyslexia-SpLD used in this study recognises and draws from the literature and debates around dyslexia, its focus on literacy difficulties, but also acknowledges that for the many of children with the profile they will have a range of concurrent difficulties and differences (Rose, 2009; Snowling, 2005) that informs their lifeworld and access to education. This also acknowledged one of the fallacies illuminated through the literature of dealing with literacy difficulties which impacted upon intervention, namely it was a specific circumscribed problem with only specific impacts, that could be addressed in isolation.

Education

While Dyslexia-SpLD is a lifelong profile (e.g. Miles et al., 2006), it is in the education setting where children typically learn to read and write, and use that capacity to access education and achieve potential with respect to securing both academic outcomes as well as the social and personal skills to launch their navigation of adult life. As explored by Deacon et al. (2020), for children with dyslexia the experiences they encounter and the ways they understand those experiences can have significant impact on their sense of self and personal confidence, long after leaving education. Education is also the setting where notionally intervention in the form of strategies for remediation is delivered. Taken together the focus on formal education is relevant for two reasons. Firstly, as Deacon et al. (2020) note, it functions as a setting that provides a gateway to social inclusiveness, though capacity to have economic and social independence. Secondly as they further note that links with how a sense of self is shaped or facilitated through education experiences. Despite its time limited nature, the importance of the education setting is in shaping how effective the identification and remediation of socially essential skills are; and how post education inclusion is constructed and accessed. Consequently, a focus on the education setting as a site of relevance to inquiry is appropriate.

Describing education and learning

While the terms education and learning can be used interchangeably in common parlance, they are different. As Thomas (2013) outlines, learning, which is the business of the education system, harnesses the natural evolutionary drive of adaptation through knowledge. The process of learning can be shaped by external framing such as obligations in acquiring and demonstrating certain forms of knowledge, as in school curricula (cf. Levin, 2010). Or it could be driven by intrinsic interest in a topic. The theory and research informing understanding of learning has been well documented, with psychology being instrumental in the field through pedagogical studies (Thomas, 2013).

Education as the term used in this thesis comprises two interactive drivers from the establishment's perspective: the process of learning within a context of school (or other recognised awarding settings), and the policy and legal frameworks, which drive structure and provision. Both aspects and their inherent conflicted and contested positions have been well described by Daniels et al. (2019) for policy and legal, and Thomas (2013) for education. However, the process of learning in education is not just limited to formal settings and structures but also includes informal times within the formal setting and, salient to this study, informal and community locations.

The legal framing of education and special educational needs

The UK Parliament (UK Parliament, 2021) identifies education as a legal and policy construct that was anchored in legislation within the late Victorian period, with 1880 marking the early start of what is recognised today as universal education. The legal framework provides a mechanism for social replicability, supporting the local and wider social structure as well as the boundaries of the state's responsibility for that aspect. The original upper age boundary for education has progressively expanded from age 10 in 1880 (UK Parliament, 2021) to age 16 in 1972, and most recently 18 in 2008, when obligations for children to have education or training until their 18th birthday came into force.

The legal and policy constructs that underpin the education system have force but can be in conflict resulting in contested space between the various parties involved. The legal system also generates as a by-product a number of physical and social structures that includes places of learning (schools or alternative provision or home) and obligations on parents to ensure their child receives an education, and requirement that the executive branch, through Local Authorities, ensures that places for education are available (Wolfe & Glenister, 2020). The policy framework includes a standards agenda that frames both evidence of learning through absolute and relative progress, quality of provision and financial obligations for schools to maintain a balanced budget. Various regulatory and inspection systems are used to ensure broad compliance (Daniels et al., 2019).

However as Daniels et al. (2019) illustrated, there were 'incentives' within the system that had the effect of reducing inclusion and diversity through perceived financial penalties for acknowledging and meeting need. Some of this arose from a raising standards agenda; schools were judged on academic achievement, and that combined with the requirement that schools had to pay the first £6,000 of SEN support per child before Local Authorities would provide additional support (Hutchinson, 2021). Although need was generally readily seen for complex and behavioural needs, the same cost features also applied to less visible disabilities such as dyslexia-SpLD. Indeed in 2019, 42.3% of those with Education Health and Care plans (EHCP) receiving additional funding from Local Authorities there were categorised as Autistic Spectrum Disorder (ASD) or Social, Emotional and Mental Health (SEMH), compared to 3.6% of those with specific learning difficulties (SpLD). This was despite 12.5% of those identified with SEND being categorised as SpLD and receiving school support. In contrast, ASD was just over 10% and SEMH was 17% of the same group (Gov.UK, 2019a).

What this highlighted is that for many children with dyslexia-SpLD their need was characterised as not severe, did not merit specialist support, and that prevalence and presence

was low in the official system. The focus on SEMH at Local Authority level at the expense of literacy and communication was also noted by Hutchinson (2021). This points to a crucial structural gap in the provision for children with dyslexia-SpLD, namely if schools are unable to support, there is not a straightforward accessible pathway to additional support open for the parents and school to access.

The drivers of education

In a review of the history of education, Thomas (2013) draws out some important themes. Firstly, that across the millennia the focus of education has remained remarkably consistent, covering the capacity to communicate in spoken and written form, mathematics-logic, cultural appreciation and expressive skills, and some form of physical body maintenance. Current curricula conform to those common areas, the point of departure being the specific level and depth of a topic culturally located in each age band. A second theme across time was the teacher as technician or as artisan in their shaping the educational environment. The theme explored how delivery of a programme of study lay and was intrinsically directed by the teacher or shaped externally. Along with the recognition and capacity to draw upon individual judgment and to construct the learning this pointed to different forms and levels of agency as part of the professional construct of the teacher.

This point of variability and agency was explored by Levin (2010) when examining efforts implementing large scale literacy improvements on a national basis in Canada, England and Wales and the need to direct change. The third theme is how education is situated within a context of both family, community, and wider environment, as well as a process of individual development, where combined influences may shape outcomes but are unseen and unrecognised, with displaced impact on both the individual and wider social context. This point will be picked up again in the parent's section of the review.

Bronfenbrenner, ecological systems theory of development and biopsychosocial model

The literature review has so far alluded to how multiple forces act to shape the individual expression of difficulty and contingent consequence linked to dyslexia. There are two well recognised overarching systems theories of development and health that speak to this observation of interactivity. They were instrumental in changing perspectives around development and health, both of which have been sub-themes in the literature review and will be considered further in the following sections. The first was Bronfenbrenner's 1979 ecological systems theory (Shelton, 2019) and its later iteration as Bioecological systems theory (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Evans, 2000). The second was the biopsychosocial theory articulated by Engel (Borrell-Carrió et al., 2004).

Bronfenbrenner's model had complexity but in the following figure as an example, Leitão used the 1979 version of the model for parental and child experiences of living with dyslexia in Australia, within it and through that illustrates the nested spatial elements of the theory.

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Figure 3 taken from Leitão et al. (2017, p. 324) "Figure 1 Examples of content pertinent to levels of the ecological model as proposed by Bronfenbrenner (1979)".

The initial systems in 1979 as described by Shelton (2019) were

- Microsystem, the immediate environment for a child in context for example child in class,
- Mesosystem which covered how a range of interacting systems at the microsystem level, e.g. child in home, class, social context then interacted further.
- Exosystem considered how environments that the person does not operate or is located in directly, nevertheless influence and shape the events and experiences at the microsystem and mesosystem level (for example policy and administrative system settings impacting on provision and options for a child)
- Macrosystem which provides the overarching cultural and wider social context including the way in which pattern of similarities in ways people express their ways of living, creating art and values.

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Figure 4 Taken from Bronfenbrenner & Ceci (1994. p.581) "Figure 3. The bioecological model for developmental competence as outcome"

Later in 1994 Bronfenbrenner and Ceci sought to reposition nature-nurture constructs and focused less on space and more upon the changes occurring through and across time influencing the transition of a person's heritability (h^2 in the figure above) through environmental engagement.

The later systems added in 1994 as described by Shelton (2019)

- The Chronosystem dealing with the passage of time and acknowledges how the changes occurring across time are reflected in the different ways the individual

functions within or engages the different levels suggesting a dynamic system both across level of environment and context as well as time

- Proximal processes dealt with the activities or events that the child engaged in directly. They did not reference child agency, rather it was the pattern of activity located in developmental process of seeking comfort, safety, substance, or exploration. Distal processes were those that indirectly impacted

The biopsychosocial theory articulated by Engel (Borrell-Carrió et al., 2004) took as its foundation that health, wellness, and disease were not limited to biochemical systems within the body or that there was one shared objective reality about that health status. The model took as its starting position that health status was not privileged by the individual's biology or biochemical status although important, but also that it was dynamically shaped by psych-emotional states and environment broadly defined. It has significant impact on the orientation of the field of medicine and therapeutics (Borrell-Carrió et al., 2004).

In relation to this study all the systems outlined are implicated in securing inclusion for children with dyslexia- SpLD. Proximal processes include learning to read and write, temporal changes are implicit across the span of education, and systems and structures form the ecological systems theory surround the child and their family.

Defining special educational needs and dyslexia-SpLD

Within that landscape is how the law in England and Wales positions special educational needs (SEN). Special educational needs are relational in education; it exists only in the presence of special education provision (SEP), which is provision that is additional to or different from what is ordinarily provided (Wolfe & Glenister, 2020). If provision is not made the need is not identified and rendered invisible in the system and allocation of resources. However, it is worth recognising that despite the cumulative evidence of dyslexia-SpLD and its impact on education and life course, it was not until 1987 that the UK government acknowledged dyslexia as a specific profile.

The Government recognise dyslexia and recognise the importance to the education progress of dyslexic children, their long-term welfare and successful

function in adult life, that they should have their needs identified at an early stage[...] I know that there are some local education authorities, which as a matter of policy, refuse to accept the word dyslexia. They argue that there are very few children who present a common pattern of dyslexic symptoms. Certainly, there is no one characteristic which defines a child as dyslexic or not dyslexic. There is a range of criteria, and a child who shows a particular pattern of difficulties may be termed dyslexic.

Robert Dunn Under Secretary for Education (Hansard : Commons, 1987, p. column 953)

The current position, both in academic and practice fields, is around recognising a specific set of children with dyslexia-SpLD/literacy difficulties. What constitutes that group (Snowling et al., 2020) and the degree of agreement about identification of needs as being additional to ordinary provision, and at the perceived expense of others (Elliot & Grigorenko, 2014; Gibbs & Elliott, 2020) has persisted as a strand of argument throughout (Kirby, 2020b). Further some Local Educational Authorities/Local Authorities who had the devolved responsibility then, as now, reluctant to acknowledge the profile (Kirby, 2020a), for a recent example Warwickshire County Council's stance resulted in a debate in the House of Lords (see appendix C for transcript) about the recognition of dyslexia-SpLD following the publication of a council policy-guidance document that disputed the existence of dyslexia or the relevance of the term. Underpinning the contested space are notions of fairness around allocation of resources to the individual versus the wider social group. However, these debates rarely refer to parents, but are presented as a contest of academics, with parents or their representatives been viewed negatively by at least one side of the debate. (Kirby, 2020b). Dyslexia-SpLD in school education is also positioned by many other multiple intersecting special educational needs. The mixed complexion of a class or school will situate a child by their 'within characteristics'. However, they are also located by others in the class who have their own profiles and multiple additional special and social needs, and the presence and profile of both vary across the location and span (Gov.UK, 2019a).

Differentiation as a tool for meeting multiple needs in shared learning spaces

One of the strategies that has been used to address the multiplicity of competing needs occupying shared physical space of a classroom is the use of differentiation. A critical evaluation of differentiation by Taylor (2017) identifies both the theoretical and pragmatic constraints such as the theoretical inability to separate ability grouping from differentiation (with the consequential impact on social identity), and the pragmatic impact of the amount of preparation required to execute the strategy effectively loading on teachers. They also note that the quality of evidence to support the use of differentiation with respect to learning was limited and weak. However Smale-Jacobse et al. (2019) in a systematic review for senior school (secondary) education concluded there was a small to moderate effect of differentiation on academic attainment. In another linked study Deunk et al. (2018), reviewing mathematical and language performance in 21 empirical studies, examined effects of differentiation on outcomes for primary schools, and found that while there were small to moderate positive effects overall, for low achieving students in homogenous groupings, the effect was a negative one. Partitioning children into smaller groups is a practical solution, but the groups' profile of progress and attainment demonstrate the impact is not evenly distributed, and, from the data, has the potential to disadvantage the most in need.

The changing nature of needs in schools

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Figure 5 The prevalence of types of special educational need common to mainstream showing as a percentage the upward trajectory of SpLD. Taken from school census 2019 (Gov.UK, 2019a)

In the figure above the key change point between age 10-11 marking the end of primary education, SpLD is the only one of the categories that cumulatively increases at that point. The numbers of pupils classified with SEND changes with the age of the child. This is from 2019 data, the public format for reporting 2020 data changed but the underlying qualities remained the same (Gov.UK, 2020a). As indicated above an EHCP attracts Local Authority support for those whose needs were beyond the school's capacity to address on their own at school support level. For dyslexia-SpLD there is an ever-progressive upward pressure, and this distinguishes it from the other identified SEN which either remain relatively stable past Year 6 of primary education or decline. It is a moot point if there was a real decline in that the problems had been resolved, or if children with needs were moved to other categories as service boundaries and presentation shifted. In 2020 there was a 10% increase on the prior year for those with an EHCP for SpLD, but this still remained under 10,000 pupils out of over 8 million (Gov.UK, 2019b), a rate of around 0.125% of the total school population. This has to be placed in the context of the notional rate of dyslexia-SpLD in the population around 8% (Macdonald, 2019). While the lack of an EHCP does not indicate that a child's difficulties have

not been recognised that discrepancy is suggestive that the nature and extent of the difficulties may have been underestimated and indeed overlooked, and that concurs with many of the parental accounts in the data. The potential under recognition is not limited to England. In a national study Barbiero et al. (2019) also identified similar in Italy through direct testing of children across the northern, central and southern regions.

The combined English data hints that as demands in the curriculum increase a gap opens in a child's capacity to maintain parity and the differential becomes visible. The findings in Hutchinson (2021) that children in larger class sizes were more likely than those in smaller classes to be identified with SEND was in part attributed to the lack of capacity of teachers to maintain and deliver support for larger groups. Applied to the national data as children progress up through school the expectation of their agency and skill will advance and workload for teachers will be set accordingly. The children's capacity to compensate in the manner suggested by Muter and Snowling (2009) or teacher ability to adapt for their differences in processing could result in clarity of difficulty and identification of need. There is also the reality that access arrangements may need to be activated and this could sharpen perception around need.

One interpretation of the data is that there has been progressive failure and potential underperformance preceding it, this identification is the marker of cumulative under recognition. The other additional factor is that while children identified as SpLD underperform on academic outcomes with only 18.1% of that group securing good pass of grade 5-9 in comparison to those without SEND with 48.2% secure the same (Gov.UK, 2020b), suggesting a gap in appropriate support and provision. Occurrence of the recognised phenomena of first diagnosis at university supports that position (Gibson & Kendall, 2010). However, it is also the case that the profile of educational attainment and progress also varies across the geography

of England (Johnson, 2020) so there is additional unevenness baked into individual and local variability of which school a child attends (Hutchinson, 2021).

Inclusion in education

In the account of dyslexia-SpLD discussed above, a complex picture of competing and contested needs and individual differences emerges (e.g. Galuschka et al., 2020). Personal accounts by parents and pupils in Gibson and Kendall (2010) are consistent with those of Norwich et al. (2005) who describe the intersection of policy-legal and individual learning, outlining how the realities of functional differences and capabilities come up against claims of meeting need. The impact and consequences remained at the individual level. However, expectations of an inclusive education system meant that children and teachers and parents were required to navigate a system which had weak capacity to provide the support required, and meet the demands placed upon it. The role of inclusion in education and for dyslexia-SpLD pupils is considered next as it forms the social-philosophical milieu in which education is delivered.

Groups and their formation: the social psychology of groups

From a social psychological and anthropological standpoint, it is recognised that humans are social animals, predisposed to operate in groups, and that such groups require multiple levels of communication, have entry criteria and boundaries, and once in the process of formation operate dynamically (Hudelson, 2004). Exclusion and prejudice have also been widely studied with reference to intergroup differences, social identity, and the discursive resources used by individuals and groups (Billig, 1985; Haslam et al., 2012; Neville et al., 2020; Reicher, 2007). This work has explored the many ways identities that are resourced for the self through multiple channels and reference points. Exclusion from a group is a known source of harm (Danforth, 2008; Turner, 2001) and this is at the wider social participatory level of which groups people identify with, are identified by, or are excluded from.

How discrimination occur between groups, and what conditions facilitate it, has been studied in terms of the characteristics of the people involved and how people group together. What is often overlooked is the key finding from Tajfel's (1970) minimal group study that "Apparently the mere fact of division into groups is enough to trigger discriminatory behaviour" (Tajfel, 1970, p. 96). This seminal study of behaviour demonstrated that independent of any qualities the group had, or what the features of the group were, the simple act of allocation to a group and its formation resulted in behaviours where participants were willing to create disadvantage to themselves if it could create greater disadvantage to the other group. The creation of difference was key. Tajfel also noticed fairness was a quality of decision making, but that it could be set aside in relation to normed behaviour. He closed his study with the observation that formation of teams and groups in education could have unintended downsides that required reflection.

The contribution of education inclusion to society

Inclusion is more than individual social acceptance in a school class. It is also about wider social justice issues which include the maintenance and quality of democracy, a point raised by Dewey back in 1922 (Danforth, 2008). It includes a sense of flourishing socially, membership, shared space and longer-term health and wellbeing along with limitations to inequalities. An essential quality is capacity for security; and in the real world this includes through employment at the individual to national levels (Danforth, 2008; Johnson, 2020).

Johnson (2020) identified the degree to which there were regional variations in the quality and access to education and these linked to regional variation in outcomes and wider impact on a region. The two Marmot Reviews (Marmot, 2010; Marmot et al., 2020) examining health inequalities and their consequences identified how education and particularly for younger children mediated the long term outcomes for life chances, health and wellbeing. Further, the benefits of it play a central role in the health and wellbeing of children at both the individual and national level. Having unremediated structural barriers to education through

disability or differences in learning were observed as longer-term sources of exclusion as well as having individual and wider social costs. Those individual barriers could also interact with other structural ones. An example of this were the links between poor literacy and poverty as described by Deacon et al. (2020) in their study of a strategy to try and raise literacy levels on a wide scale basis for a group of Scottish pupils with poverty indicators, and in the account of the Labour government 1997-2010 attempts to do the same (Levin, 2010). The recent work of Hutchinson (2021) the ways in which various structural features such as individual poverty and socioeconomic status of area, heritage and culture and the degree of academisation in an administrative area all influenced the rate at which SEND was identified. Some of those factors behaved counterintuitively. The significant deterrent of identification of SEND was which school a child attended, pointing to the impact of very circumscribed local factors in the context of wider ones.

This then is the ethical and socio-political framework where individual possibility in the form of capability, and reality in the form functionality, are held in tension (Reindal, 2010). As Haug (2017) noted inclusion needs to deal with vertical inequality which relates to an individual level (and which the law attempts to address), as well as horizontal inequality where groups have less favoured treatment by virtue of a characteristic. The implication of adopting an inclusive culture and stance is that there should be reduction or removal of barriers in both planes that systematically result in exclusion or 'othering' and challenges to the limits of capability through functionality (Haug, 2017; Reindal, 2010).

The definition and framing of inclusion.

In their overview of the framing of inclusion for English education, Lauchlan and Greig (2015) trace through the policy developments that have shaped the current conceptions in education. They reference the contested space between universalists who take the stance there should be no special school education provision, and moderates who accept that it may

offer the best chance for an individual child to achieve quality education. They offer a general description of inclusion as:

It is generally taken to mean that children and young people are included both socially and educationally in an environment where they feel welcomed and where they can thrive and progress.

(Lauchlan & Greig, 2015, p70)

That broad description highlights the many issues linked to inclusion, firstly that it is multidimensional, secondly, that it involves undefined others as part of the description, and thirdly a lack of clarity about the nature of inclusion.

As they note, inclusion has formed part of the legal policy and practice framework permeating education as exemplified in the Special Educational Needs and Disability Code of Practice :0-25 [CoP](Department for Education, 2015). However nowhere in the legal framing of the CoP is inclusion defined and described. It is broadly understood legally across the many case law judgments (cf. Wolfe & Glenister, 2020) as a child having comparable access to opportunities for: learning and development, resources, space, education processes, and having needs met within the context of a legal obligation to access an “appropriate education” (Wolfe & Glenister, 2020, p. 5). But is not defined, indeed across the review of the case law as it stood in 2020 there was only one reference and that was:

It [LA] has to provide for the identified needs. It cannot say that it will educate the child in a mainstream school without providing for them. Nor can it rely on any independent resources issue in this respect. This combines the need to protect the interests of the child with Parliament’s intention, in amending 1996 Act in 2001, to promote inclusion (para 27).

(Wolfe & Glenister, 2020, pp. 41-42)

Inclusion as addressed through the legal system is located at the individual child level, not the class or school level or Local Authority level. Obligations on local authorities (LAs) and schools to promote and secure inclusion are referenced in sections 3, 5, 6 of the Code of Practice 0-25 (CoP) (Department for Education, 2015) with section 6.8 and 6.9 of the CoP

providing some directional clarity around the obligations, if not the term itself, which are wide ranging from institutional and service access for children and families to design of curriculum. These include an obligation to *“review and evaluate the breath and impact of support”* they offer (Department for Education, 2015, p. 93, section 6.8), and *“They [schools] must make reasonable adjustments, including the provision of auxiliary aids and services for disabled children, to prevent them being put at a substantial disadvantage. These duties are anticipatory”* (Department for Education, 2015, p. 93, section 6.9.). And again in the same section *“Schools also have wider duties to prevent discrimination, to promote equality of opportunity and to foster good relations”* (Department for Education, 2015, p. 93). In combination, the thrust of the CoP (Department for Education, 2015) with respect to inclusion is about accommodation through additional support, either equipment or persons, but also in the culture of the setting and engagement of parents.

Background to the development of educational inclusion and Special Educational Needs

While the ideas of inclusion in education pre-dated World War II, it was only with the Warnock report in 1978 that the significant shift in UK legislative policy occurred, leading to the 1981 Education Act (Lindsay, 2003; Lindsay et al., 2020). Although, as (Lindsay, 2003, pp. 4-5) points out that at the frontline level, various organisation had evolved individual or local practice; to address perceived limitations prior to the committee report and Act. Those observations and findings informed the committee’s thinking. This shift was from partition in education through diagnosis/disability which had been the practice under the 1944 Education Act to integrated mixed profile education. The UK process also drew upon supra-national shifts exemplified by the United Nations call for the International Year of the Disabled Person raised in 1976 and celebrated in 1981

(<https://www.un.org/development/desa/disabilities/the-international-year-of-disabled-persons-1981.html>). As Egelund and Dyssegaard (2019) reported, the impact of Warnock’s

work went beyond the boundaries of the UK and had presence in Denmark, indicative of its paradigm shifting nature.

The contribution of the Warnock committee

The overall recommendations and thrust of the Warnock report framed the 1981 Education Act, that also provided the expectations and mechanisms for achieving the implicit aim of inclusive education. The Act also created the definition of what became Special Educational Needs (SEN) (Lauchlan & Greig, 2015; Lindsay et al., 2020), later referenced as Special Educational Needs and Disability (SEND). SEN were defined as having arisen when Special Educational Provision (SEP) was required. The SEP occurred when “young persons for whom standard educational provision will not suffice” and they therefore required education that included “additional to or different from” what was originally positioned as ordinarily available (mainstream) and later was ordinarily provided in England (Wolfe & Glenister, 2020, p. 12). The legal threshold centred on differences in provision is still the one that stands to date. A child has SEN if SEP is provided. It has circularity in identification.

Overall, from Warnock there was recognition that inclusion was something to be negotiated and achieved in partnership with parents (Lindsay et al., 2020). However, the legal framing that emerged was that parental views and choice was constrained in the context of the public purse, had costs attached to it, and this was teased out over time through various case law precedents (Wolfe & Glenister, 2020). Implicit in the Warnock Report and the legal framing was that inclusion also involved disruption for the larger group, and involved provision of something different (Wolfe & Glenister, 2020).

The contested zone is what does ‘standard educational provision’ entail and this also has impacted upon the way research has been framed. The common constructions of inclusion accessed by researchers also are a reflection of Warnock’s report, and of notional ‘standard education’ often using a temporal-spatial perspective of people located in spatial proximity

and time as in attending a class or a school as a form of inclusion, captured by Göransson and Nilholm (2014) first level of inclusion as child with disabilities having a presence in the classroom, or alternately by the negative of 'not exclusion'. This will be expanded upon in the next section.

Inclusion in educational research and practice

For such a widely used phrase, inclusion presents as a fuzzy concept, which has challenged researchers wishing to explore its relevance and impact. This latter point was the conclusion of Göransson and Nilholm (2014) who systematically reviewed and conceptually located how researchers had formulated inclusion. As a term, inclusion is contested, defined and constructed in multiple ways, with the preponderance of narratives in the literature in favour of inclusion but importantly not all (Dahle et al., 2011; Göransson & Nilholm, 2014; Lauchlan & Greig, 2015; Nilholm & Göransson, 2017; Sandoval et al., 2021). Notably Lindsay (2003) in his review of the inclusion field identifies a cumulative body of evidence that suggested the broad-based universal benefits of inclusion had been over-claimed. Further, evidence of benefit to children with disabilities and differences was at best marginal and findings from some studies demonstrated it was counterproductive. The review highlighted the range of different models of inclusion and the degree of interactivity between the child and environment on experiences and outcomes.

A different approach was adopted in the review of the constructs of inclusion expressed in the literature by Göransson and Nilholm (2014). They focused upon how teachers had defined the concept in their work. They identified four linked and nested constructs to describe inclusion: placement of child in classroom, meeting needs of child, meeting needs of all children, creating a community. The first level is a metric, the child is or is not in the classroom. The next two are subjective around meeting needs at the individual and group level and equate to common conceptions of inclusion, but the framing is still spatial in terms of the class and classroom. The final one speaks to the organic ways groups and communities can

evolve, school/non-school community ethos, and is about how degrees of connectivity, compensation, and diverse group identity meld together. It references ideas of being “welcome” by Lauchlan and Greig (2015). One of the practical issues in this hierarchy is that at the first level exclusion is relatively easy to identify as an individual who is explicitly outside the major group. Lack of inclusion at that level is only about having a presence, it is not about meeting need. In contrast there is less clarity in the other levels about knowing when inclusion has been achieved. Inclusion in levels two and three is led by the class teacher, while the final level suggests the leadership role for meeting needs has shifted from the teacher to the group.

Inclusion broadly considered: School structures and other matters shaping inclusion

An important part of the tensions around educational inclusion are how schools of varying sizes and ethos have pupils selected for them, or how they select; and then how they choose to manage the cohorts within the school (Lindsay, 2003). When references are made to inclusion, which reference group forms the principal group is not always clear. This lack of clarity was illustrated by Göransson and Nilholm (2014) who used the class group for the first three levels; which is both a space and grouping as the reference point, but left open the fourth as community. At a practical level this means there are multiple reference groups. Schools’ administration and functionality is based on assigned groups. These can be age related as in the case of primary education, but also at that phase include different size groups, small to full class size, and subdividing by core subject ability. In secondary schools this can be extended by performance related to class or specific subject level, or based upon functionality in key subject areas (e.g., English or maths) that then position a child with respect to the whole curriculum organisation (e.g., secondary school sets).

However the structure both internal and external to the school as a unit of education can facilitate exclusionary practices (Done & Andrews, 2020) that position children in negative way; and do so in the context of vulnerabilities (Ellis & Rowe, 2020). The latter study

highlighted how children came into school each day with a differing range of skills & cultural tools (they reference it as their personal satchel of tools), and social-educational support, and that each child started the day from differing positions, that had been cumulatively built up over their brief lifetime. In their study Ellis and Rowe were examining how the educational gap that linked poverty and literacy could be addressed, in this case poverty, a causal factor outside the school's direct control, while literacy was potentially within it. The range of individual variability was important as it illuminated how the decisions made by schools or teachers were not in a neutral context. This further reinforced Lindsay (2003) point about the interactivity of factors that are in play for a child. The focus on this variability has been at the child level, and to a lesser extent the school grouping. The features of the regularities of the system the child is placed within have not been a focus of inquiry; in particular, the role of systems such as the educational arm of Local Authorities and the kinds of structures that shape school provision and learning architecture.

[Inclusion, labelling, and labelling with respect to dyslexia-SpLD](#)

For inclusion to initially occur for a child with dyslexia-SpLD, a person or group needed to make the decision that something different was required, for it to be initiated, and the view of what kind of 'different' shapes the nature of inclusion and the experiences it offers. As Hartas (2011) noted, a disconnect can occur in education between the intentions of those implementing inclusion and the experiences of it, leading to disaffection and disengagement. Hartas (2011) concluded from her study of a group of teacher-identified disaffected youth with regards to what is good for a group, inclusion must be defined by both those in authority and those being included. She went on to suggest that disengagement is a form of self-exclusion. However, its origins as Hartas (2011) notes may lie in more subtle and structural aspects about the relevance of the environment to the person, and this is an aspect that builds over time. This suggests that the evolution of what could be described as 'failing inclusion' could have

multiple trajectories and contributing factors over time and would require longitudinal studies to explore.

In association with the evolution of inclusion is the issue of labelling, how it occurs, and its impact on the formation and regard of groups. A presumption held generally in education was that the label itself was a source of stigmatisation (Riddick, 2000). And this gave rise to a strategy of avoiding labels. Within this context educational labelling has and continues to be a strand of inquiry. While Lauchlan and Boyle (2020) outline the key debates on the utility and effect of labels for children in education, one of the contested areas was the role an ascribed label played in potential stigmatisation.

As Kirby (2020b) pointed out in his historical account, those with dyslexia-SpLD and their advocates were keen to lay claim to the label as it offered a form of social recognition. There were broadly two groups, those opposed to identification, and others taking a different view. Riddick (2000) has argued that stigmatisation could precede the label for those with dyslexia-SpLD, rather than the stigmatisation following the label. Lauchlan and Boyle (2020) presented evidence of how the dyslexia-SpLD label has been challenged by some academics and practitioners; but they also presented evidence of how the label has been viewed positively by both those with the profile, lived experience and parents of children with dyslexia-SpLD. One reading of their evidence presented could suggest that the label of dyslexia-SpLD supplanted other more negative ones such as “stupid”:

It had a name, I wasn't stupid, the psychologist said I wasn't stupid, and it was a lovely feeling

(Riddick, 2000, p. 659)

However, this aspect of replacement labelling, of accessing alternative identity explanations, was not identified or explored by Lauchlan and Boyle (2020). This section of the literature regarding views on inclusion and dyslexia-SpLD has not dealt with the academic contested position around narrow cognitive interpretations of dyslexia-SpLD referenced by

Lauchlan and Boyle (2020) or Deacon et al. (2020) which are briefly addressed in the section covering dyslexia-SpLD, instead it has focused upon a broadly understood profile of dyslexia-SpLD, in the manner of Hartas (2011) identification of children with school disengagement difficulties been generally recognised by others/teachers. this is also consistent with Snowling et al. (2020).

Proximity and fractured academic identity

Accounts of inclusion dependent upon peoples' location being close (proximity accounts of inclusion) assume that diversity is not only a good thing but a necessity. Ergo, the presence of difference within groups is for the wider group's benefit (Paluck et al., 2019; Turner, 2001). Benefits are also assumed to flow from acceptance of diversity. In combination both factors represent accounts of emotion, tensions, and dimensions of inclusion broadly described. However, those assumptions are subject to scrutiny. It is not clear from examining the literature notably with Lindsay (2003) who highlighted the over claiming of benefits of inclusion that the assumed gains accrued by the majority are matched with equal benefits for the individuals with dyslexia-SpLD joining the group concerned.

This is also true in education whereas Lithari (2019) noted fractured academic identities could arise for pupils with dyslexia-SpLD as a result of the interface of their profile and interaction with the people and systems. In contrast Knight (2021) in her propensity score matching analysis of the millennium cohort study, argued that it was the diagnosis of dyslexia-SpLD that was the causal feature of poor academic self-concept. However, Knight (2021) makes the assumption that children assessed as being of the same academic performance level were having the same educational load and experience. There is not good evidence to make that assumption. Other work such as Lithari (2019) would challenge such assumptions. However, the work does highlight how decontextualized studies can both illuminate and obscure a complex picture. The resultant risks identified by Lithari (2019) were not confined to England or the UK but were found transnationally. For example, accounts of bullying and

teasing for children with dyslexia-SpLD highlight this (Andreou et al., 2015) and more recently in the adult accounts of schooling both pre and post the 1981 Education Act (Deacon et al., 2020). Across time and literature, a consistent portrait of fractured identities for this group of pupils is captured (Carroll & Iles, 2006; Carroll et al., 2005; Evans, 2020; Ingesson, 2007; Leitão et al., 2017; Livingston et al., 2018; S. Macdonald, 2009b; McNulty, 2003; Polychroni et al., 2006; Riddick, 1996, 2000, 2010; Zambo, 2004). This would appear to be the lived but less acknowledged reality of dyslexia-SpLD for children and their families. It is lower profile in part because the preponderance of literature for the field is with respect to reading/spelling/writing, and the implicit assumption that resolving those difficulties will also resolve additional psychological ones.

A recent review of the research however by Snowling et al. (2020) acknowledged this classic view of causality suggests mechanisms for resolution of difficulties. They cited evidence of childhood internalising problems and mental health problems linked to reading disorders - some of this is cited above. That line of causality would suggest the resolution of one factor, in this case literacy would improve the other, mental health. However this does not take account of the idea that there could be the creation of emergent properties, whereby the consequences of an impairment profile which could include inattention as identified by Carroll et al. (2005), interacting with environment produced an independent factor, in this case raised risk or generation of mental health difficulties.

Snowling and Hulme (2020) also identified evidence suggestive that in some cases mental health disorders were comorbid; they were coexisting but not causally linked to the dyslexia-SpLD. In Carroll et al. (2005) study they also found that for children with a predisposition to anxiety the interaction with the literacy learning difficulty predisposed to the full expression of a clinical anxiety state suggestive of an additive form of risk. Other studies have found that those with dyslexia-SpLD had much higher prevalence of mental health

disorders, which extended into adulthood. In summary the consequential chain of impact from reading and spelling disorders is less linear with greater complexity than may have been understood.

The impact and role of diagnosis and labelling in mediating social stress.

Other work such as that cited in earlier sections of the review have considered matters of labelling from the perspective of its application to dyslexia-SpLD. The latter group of work has been useful, but as Lauchlan and Boyle (2020) observe it would be helpful to know which parts of the education-inclusion-labelling experiences are shared and thought beneficial across profiles of difference, and which are specific, in this case to dyslexia-SpLD.

Inclusion in this framing has considered matters from within the school, and from the child-teacher axis, generating a substantial physically (school-based) circumscribed construct of inclusion. Although Lauchlan and Boyle (2020) included matters relating to parents, it was with reference to the issue of labelling (as that was the focus of the work) rather than wider inclusive education. The work acknowledged the benefit parents and children derived in the use of labels such as dyslexia-SpLD. However, the subtext of the benefit was suggestive of a non-consequential psychological sop for parents, with limited relevance to the real business of education for these and similar children. What was not considered was how the parents' perspectives of the utility of the label may be an important challenge to the assumptions about what the real business of education and inclusion was, and what role the parents could play in such inquiry.

A systematic review by O'Connor et al. (2018) examined the protective and risk role of diagnosis (including dyslexia-SpLD) to self-concept and to self-identity, generating thematic maps for both risk and benefits for both aspects. It illustrated the complexity of factors but also noted that "On the positive side, diagnosis can provide a sense of relief and self-understanding by implying symptoms result from a 'real', independent disease entity"

(O'Connor et al., 2018, p. 95). Thus implicitly identifying a role for epistemic justice and injustice through disadvantage or prejudice (Byskov, 2020), for the child and their sense of self. Lithari (2019) found that in her study a case where the information relating to the diagnosis was withheld from a child and the difficulties the young adult felt when she found out the information was withheld. This relief and anger at failure to identify and diagnose had been reported elsewhere and even resulted in legal cases (Konur, 2006).

However, Lithari's (2019) study explicitly explored the specific case, and one reading of the account which is only tentatively and partially alluded to, is that it suggests how a diagnosis is a resource of self-forgiveness and understanding around the self for the child and young person's internal dialogue in line with Archer (2000). What was more robustly identified was how it was a counterfactual against negative social positioning. Other studies such as Ingesson (2007) found mixed picture of responses to the initial communication of diagnosis, some positive others negative but this also found that many did not understand what the diagnosis meant, again suggestive that the primary value of the identification process for the child was it was a resource, of use if it had explanatory properties.

Research on Inclusion specific to dyslexia-SpLD versus general SEN

While dyslexia-SpLD is embedded for classification purposes within the group of special education needs, it is not the case that it shares so many characteristics with the wider group to have easy compatibility other than difficulty in securing access to education. Although there are recognised major groups within SEND (see Figure 5) and have their own profile of recognisable pattern of difficulties, it is the case that patterns of shared features of co-morbidity's can occur for example Carroll et al. (2005) identified ADHD Inattentive Type was linked with dyslexia-SpLD. The difficulty is in placing such a diverse group as a unit, the specific features of the dyslexia-SpLD profile for any given child may not be well articulated at the

group level description. In the studies of inclusion there has been assumptions by several authors that for the purposes of their research all SEN is collectively considered as a unit i.e., not specified, with respect to inclusion. The nuanced differences between the child's profile/diagnosis/presentation and forms of additional learning need support that shape inclusion is not partitioned. The comparison was between those with or without SEN. This related to the levels of analysis conducted linked to findings.

For some examples of the research the focus on a specific attribute that commonly created difficulty such as level and types of noise in a classroom on academic performance was amenable to group level exploration, as was conducted by (Dockrell & Shield, 2006) but again caution on its application to children with dyslexia-SpLD was warranted. In many cases the profile of individual forms of SEN are at such a low level if they have a presence at all in an individual school, I would not be practical to conduct research on the subgroups. The lack of specificity in some of the research has meant that in those areas the similarities and differences for pupils with diverging profiles such as dyslexia-SpLD are not easily reconciled, and the array of dimensions of inclusion and evaluation are limited in those studies to broad collective analysis of SEN in general. This has made evaluating the benefits and costs for inclusion and inclusion practices for children with dyslexia-SpLD challenging to critically analyse.

The wider international context of inclusion including recognition of need

The Warnock report recognised the centrality of parents in the optimal outcomes for their children, and the importance of engagement. However, a review of how parents of children with SEN experience the system meeting needs suggests that there remains both a gap in the report's aspirations as well as significant resistance and lack of understanding within the system both generally and with respect to dyslexia-SpLD specifically (Cullen & Lindsay, 2019; Earey, 2013; Lindsay, 2003). But this is not limited to the English system, such challenges were also found in Denmark (Egelund & Dyssegaard, 2019), Australia (Levi, 2017b), America

(Phillips & Odegard, 2017), Italy (Barbiero et al., 2019), Netherlands (de Boer et al., 2011), which suggests at a structural level having differences within a classroom is challenging for teacher competency, sense of efficacy and a child's rights. In the case of some authors (Barbiero et al., 2019; Earey, 2013; Phillips & Odegard, 2017), the findings were specific to dyslexia-SpLD and in particular the failure of schools to identify those with dyslexia-SpLD/literacy difficulty profiles. In the case of Barbiero et al. (2019) that was a substantial national study. These points of tension are not local issues but national-transnational and override the specifics of local educational organisation and provision. The baseline for inclusion, of access to the skills of literacy and allied communication appears as a persistent difficulty that crosses boundaries. This suggests that there are deep structural issues, which seem to go beyond the local solutions.

Levi's (2017b) Australian study which took a discursive approach using a social justice critical framework provides an in-depth thesis which provided a cross cultural comparator to England. It was useful for providing another view on parental perspectives around the recognition of need (and by implication inclusion) from the perspective of recognition-accommodation-access axis in the Victoria region of Australia. Her focus in this study was around parents securing recognition of dyslexia-SpLD, and of support for their child in a system that had limited or at least perceived ineffectual recognition of dyslexia-SpLD as a disability, and consequently no consistent provision or mechanism to address a disability impacting upon health and wellbeing. The study explored three different levels of need recognition (recognition, interpretation and addressing need). It focused upon the contested area between parents and schools but located that within a larger framework of need at the different political levels of school (and type of school), area, and national levels. It considered the political drivers for the recognitions of dyslexia-SpLD, then interpretation of need, before the need is addressed and then satisfied (Levi, 2017b, pp. 31-32). Using this narrative Levi

examines how that played out in the interactions between the school and parent depending upon the school and the degree of parental led provision.

Consistent with many other studies she captures an account of unevenness and contested recognition. Her study extended the field by identifying how the individual experiences were part of a wider political positioning, the contrary aspects of recognition of disability but not at the hidden disability or dyslexia-SpLD specific child level, and failures at the state administrative levels. She identified how disruption between parents and school staff mediated child access to, and engagement in, education. She also explored the difficulties parents had in securing diagnosis, support and understanding and effective outcomes. One reading of Levi's study is that it illustrated that the consequences of the contested nature of dyslexia-SpLD are wider than just a reading programme, as advocated by some academics, but are located by the way the state, in this case Victoria, acknowledges and addresses minority disrupters of efficient delivery of services.

Parents how they are seen and see themselves.

The types of research

Research focused upon parents whose children have dyslexia-SpLD falls into two broad groups and a third combining both sets of characteristics. The first seeks to represent the parent voice as directly as possible through first person accounts; Leitão et al. (2017) would be an example of that. Other research is more detached, with parents and their family setting functioning as objects of inquiry. The following examples include: parental engagement with support groups (Bull, 2003), types of complementary therapies parents provided to children with dyslexia-SpLD (Bull, 2009), the home literacy environment (Hamilton et al., 2016), and the economic costs for parents with a child with dyslexia-SpLD in India (Karande et al., 2019) respectively. These forms of studies are focused upon patterns of circumstances, behaviours, beliefs, or metrics identified.

A third type of study combines both those accounts of voice and patterns e.g. observation. An example would be Cullen and Lindsay (2019) who used the first-person account of parents navigating the Education and Health Care plan dispute resolution services, to give voice to parents, and understand patterns of experience, locating them within psychological frameworks. That work was not expressly about children with dyslexia-SpLD but about parts of the system parents may have to engage with. Both single sector and combined sector research approaches provide different insights on parental experience through different levels of analysis and perspectives of the researcher, while the wider ones can inform context. They also provide in several cases direct and indirect account of parts of the education system.

Across the literature and country settings there is both direct and indirect evidence of parental distress and stress, and this forms the focus of this section.

Parents' contribution and roles in research

Parents of children with dyslexia-SpLD have had a low profile in the research literature, with the exception of the body of work by Riddick (1995, 1996, 2000, 2001, 2010). As Norwich et al. (2005) noted, some work purportedly addressing parental perspectives did not involve them, Dyson and Skidmore's 1994 study (that asked the teachers instead of parents about parental relationships):

It is interesting that this study did not consider the parental perspectives, confirming what Atkin et al. (1988) pointed out years ago; research on home-school relationships focuses mainly on the professional rather than parent perspectives.

(Norwich et al., 2005, p. 152)

The extract illustrates how in academic inquiry the voice and knowledge of the parent had been and still is largely side-lined. The lack of ecological rigor meant there was a recognisable risk that information generated misleading accounts, which in turn created risk of misdirected emphasis or focus of investigation, and its potential application to misinformed policy.

The absence of parent voice led organisations such as British Dyslexia Association to counterbalance the research narrative through academic partnerships and alternative ecological research strategies such as action research (cf. Coghlan, 2005), for example exploring the value of a variety of forms of community support (see: Bull, 2003; Griffiths et al., 2004; Norwich et al., 2005). Bull (2003) examined how parents used support frameworks such as community groups or access to experts to fill in for missing educational support or knowledge. The study identified multiple needs and gaps impacting on parental capacities. Some parents were resistant in acknowledging their child's difficulties, and by implication illustrated how the school and services had not engaged them effectively. Parents attended community groups to improve their knowledge but also for support with self-perceptions of stress and difficulties coping. Around half the participants also identified social isolation from friends and family linked to their child's dyslexia-SpLD. Responses across the studies suggested that parents needed support around the diagnosis/ identification process to come to terms with their child's differences.

Parental distress, dealing with differences.

Parental distress and difficulty occur as part of the cross-national narratives of dyslexia-SpLD, although how it's expressed in different cultures may vary. Karande et al. (2019) conducted a study of 138 Indian parents identifying the direct, indirect, and intangible costs of supporting a child with dyslexia-SpLD. They calculated and weighted costs from data supplied to them by the parents. The costs were greater the longer poor school performance had been noted, and that the support was not just the target to literacy support but also to other aspects of the curriculum, demonstrating the wider impact across educational access. The indirect costs of wages loss, and linked time costs for support provided outweighed the direct costs 83.1% v 16.9%. The hidden costs were therefore substantial.

Again, in the study there were a small number 4.4% that despite diagnosis refused to believe their child had a disability: a finding compatible with Bull's account. In contrast a Dutch

study by Multhauf et al. (2016) explored supporting mothers of children with dyslexia-SpLD who had stress, through the use of a cognitive behavioural programme using an RCT design of intervention and waiting list controls. They reported a delayed positive response at 3 months in stress reduction and there were benefits around mother's confidence to engage, support, and motivate literacy practice. The programme included provision of information and suggested skill practice.

Leitão et al. (2017) interviewed 13 children and 21 parents in Western Australia to gain an understanding of the lived experience of dyslexia-SpLD. Reflecting the accounts of British studies by Riddick (2010), the Australian study identified a number of themes in relation to factors that shaped quality of life experience and access to education:

Parents identified the school environment as often being a challenging setting whereby the school failed to meet the needs of their child

(Leitão et al., 2017, p. 330)

Of interest, they also found incidences when a school focused upon a perceived child-centred learning approach provided positive experiences. Parents who were positioned by the system as standing outside it, also identified that the variability was not just between schools but also within. Inconsistency in teaching as a contributing factor:

Variability of teaching performance was also mentioned: "But when he's got, um, just a regular teacher that just doesn't get it, everything just falls apart, you know? So he's lucky he's had a couple of good teachers". This parent contrasts "regular" teachers with "good" teachers, and is grateful for the "luck" that the child has had a couple of good teachers.

(Leitão et al., 2017, p. 330)

The study was also useful for indicating differences in child and parent's systems engagement. The child's focus was on the immediate environments of school friends and family. The study made use of the micro and meso systems in Bronfenbrenner's (1979)

ecological system (Leitão et al., 2017, p. 324) as part of its explanatory framework. The authors noted parents engaged the same level of systems as the children plus the exosystem level which include media, law, social class, economic systems (Leitão et al., 2017, pp. 324, & 330-331). That marked a difference for them, compared to their child but also compared to other parents. Engagement, rather than co-existence at that level was required to secure support both at individual but also at community of need level, unlike most parents who may be located within the exosystem but do not have to challenge its limitations. This accords with Kirby's (2020b) account of recognition in the UK. That reasonably suggests an additional source of stress outside what the typical parent-child engagement with the education system would be. However, these qualitative differences are not well represented in the literature.

The cumulative nature of stress and strategies parents use to seek resolution was a focus of a study by (Griffiths et al., 2004) which identified a range of escalating strategies used to secure support for a child; ranging from conversations/writing letters to a school, to tribunal, or opting out of school (Griffiths et al., 2004, p. 423). The study captured how much of the work of navigating the system on behalf of child was by mothers. Action was informed by the parents (mothers) progressive knowledge acquisition, which also informed their construct of being a parent. The strategies used were escalating and initially non-confrontational, but seemingly had limited efficacy.

Norwich et al. (2005) explored the role of a development officer supporting families of children with dyslexia-SpLD navigating the school system, identifying 3 levels of interconnectivity and potential barriers between systems: for all; those for SEN; and those for diagnosis learning difficulty. The latter study was with a small cohort of seven parents and 7 case officers over two years, it did however identify pertinent themes that were reflected in later work drawing upon wider data sets. Which also support claims that small well-constructed studies can have quality findings. Accounts of other researchers still report the

persistent pattern identified (Bull, 2003; Griffiths et al., 2004; Lithari, 2019; Snowling & Hulme, 2020).

Dealing with distress interventions from research

The accounts, although limited, have consistently captured sources and experiences of parental distress, although only one example has been found of an intervention through Cognitive Behavioural Therapy- CBT (Multhauf et al., 2016) and that was also specifically directed at mothers. There was one that made recommendations for de-escalating conflict and stress resulting from empirical work (Cullen & Lindsay, 2019). However, the following extract summarises the key findings across studies.

The role of a parent of a child with dyslexia is multifaceted, but appears driven by the necessity of ensuring the fundamental education and social needs of their children are met, [...] parents performed the role where they endeavoured to provide support for their child so that they were 'less different'.

(Leitão et al., 2017, p. 331)

The extract could describe any engaged parent's role for their child's education. What is missing is the qualitative and quantitative difference of activity required to try and elicit a level playing field, to secure the basics. Ordinarily the level of activity described would be designed to provide excellence of performance, not an effort to secure minimum access. It was also the case that this support was ongoing, rather than focused attention directed at specific purposes or time periods. The continual demands did result in parental exhaustion illustrated by the following extract.

I mean, you know, it got to the point where your capacity, uh, constructive dialogue is sort of just, is exhausted.

(Leitão et al., 2017, p. 332).

It seems the case across the literature that parents have a choice with respect to their child; to do what is typical, thereby fitting in with other parents or school expectations; or to do much more than typical both at qualitative and quantitative levels to secure the basics, and

to do so against system inertia or refusal to engage but at social, inter- and intra-personal, and economic costs to the self and family.

The parent roles in respect of school, family and self

As previously discussed, some of the research is to the broader or area of SEND rather than specifically dyslexia-SpLD but can usefully inform at a less granular level trends or points of interest. Two papers that have a useful contribution despite not directly addressing dyslexia-SpLD are Tveit (2009) and Lake and Billingsley (2000). Both chime with the other recent accounts in the literature discussed so far about zones of conflict and difference as it related to the general area and history of dyslexia-SpLD, but usefully extend the analysis through detail. Both papers deal with parental perceptions but from different perspectives and methodologies. The conclusions from the above literature are consistent with the unusual document analysis study conducted by Tveit (2009) using texts from Norwegian government authorised parental reference and advisory group on primary and lower secondary education. This examined through parental voice the dichotomies and tensions between parents' expected roles exploring who shaped and defined them in relation to schools, finding that there could be marked divergence as drawn from their data:

***we know that in certain instances there may be a great distance
between the schools' understanding of the student and his needs and the
parents' views on the matter***

(Tveit, 2009, p. 295)

There was complexity in the analysis about how parents are both legally responsible for their child's education and as the author raises an intellectual case it is arguable that indirectly the teachers are in service of parents. A slightly more refined reading is they are in service of the child. However, there was also a contrary role for teachers in specifically examining needs and who accesses different epistemologies and social power to parents. The importance of knowledge was a recurring motif throughout the work.

A more direct analysis of the area was Lake and Billingsley (2000) who identified eight factors that drove conflict between parents and schools with respect to children with special educational needs. A level of randomisation in the recruitment of participants took place and the research was located within Massachusetts as they had an established dispute resolution process. The study was a qualitative one using grounded theory with 22 parental participants and 16 school officials and 6 mediators and explored through open ended interviews the events leading up to conflict, the context and what happened and what could have been done differently. They identified 8 factors that shaped escalation of conflict.

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***Figure 6** Factors that escalate and deescalate conflict for parents and school with respect to children with special educational needs. Figure 2 from Lake and Billingsley (2000, p. 244)*

Seven of the factors identified contributed into the main driver of conflict which was discrepant views of child or child needs, and this was mediated by trust. The research work relating to parents has either described experience or sought to explain experience in terms of patterns of responses as well as the nature of knowledge parents could access.

The next section addresses the gaps identified in the literature to date, by examining how methodological issues may have constrained the production of knowledge and insights. Much of the work specific to dyslexia-SpLD has provided description at either a broad level or a rich detailed level but has not provided a framework for changing what is a (transnational) persistent narrative. The next section explores how a different research approach has potential to elicit different knowledge about what parents do when they have a child with dyslexia-SpLD, why they do it, and the consequences that flow from actions to extend the depth of accounts available.

Constructs of dyslexia-SpLD in research, issues of methodology

Much of the research considered in the literature review reflects findings that are either located in the scientific domain, or the phenomenological-experiential one. They reflect well established strategies of enquiry anchored in theoretical positions of ontological and epistemological nature. Such research orientations have associated methodologies and seek to represent knowledge within the constraints of inquiry. Across both forms of investigation, a substantial body of knowledge has been generated. However, as the literature review identified there remain many gaps or areas of limited exploration. The gaps are not always because research has been more limited in the area, they occur for several reasons. Firstly, quantitative approaches require that meaningful and reliable measurement can take place. This creates a very restricted range of possible things that can be meaningfully measured, and the measurement only pertains to that areas and that set of situations for its generalisability to be relevant (Richards, 2002). Secondly for qualitative work the determination of causality or association which is the strength of quantitative work is not available as the accounts are at the individual level and they do not draw upon the assumptions of randomisation and probability essential to determine causality. Qualitative work is much more dependent upon the skills of the data gather such as interviewer, and the analysis is much more open to

challenge because of the interpretive nature and the lack of shared assumption of reality. For the latter this has limited its explanatory power

The limitation of the inquiry tools limits questions that can be asked. The methods limit what data is gathered and so what questions can be answered, or the degree to which funding support for conducting research may be limited (it was one of the reasons the British Dyslexia Association (BDA) supported some research e.g. Bull (2003)). Alternatively, because certain populations have more visibility and presence in the research, they may overshadow other populations such as hard to reach communities and requires specific skills to enable access. There was for example in the literature review substantial material to evaluate in relation to topics of dyslexia-SpLD, education and of inclusion but a paucity for the topic of parents. The limitations are also in how research strategies enable extension of knowledge for the area.

A gap in inquiry

This constraint is illustrated by the replicability of findings of parental distress for parents of children with dyslexia-SpLD and similar SEN, but few explanations as to why the distress, coupled with poor quality educational outcomes for dyslexic pupils, continues. The research findings to date are fundamentally descriptive; constrained by the research strategies that have been applied. In contrast there is a range of advice on what to do, but little evaluation of the merits of the advice, which may have weak evidence base (Carroll et al., 2017). This suggests that alternative forms of investigation that can ask different questions and produce answers that extend surface description and look to different forms of association and causality would be advantageous to examine a set of common observations extending over 50 years.

Critical realism and its potential for dyslexia-SpLD research

Macdonald (2019) identified critical realism as a mid-point on the spectrum of research strategies used by researchers in the field of dyslexia-SpLD research. Inquiry to date has shown a polarity bias, been anchored at either end of the spectrum through the biomedical & biopsychosocial at one end and the neurodiversity identity work at the other. There has been limited work making use of critical realism, indeed Macdonald along with Deacon (2020) are the only ones in the literature who has specifically examined dyslexia-SpLD (Deacon et al., 2020; S. Macdonald, 2009a; 2009; S. Macdonald, 2009b; Macdonald, 2010, 2012; Macdonald et al., 2016; 2009). As Macdonald notes, the critical realist model acknowledges that people are disabled by both barriers in society and by their bodies. He argues to understand the impairment/disablement experience of difference, both aspects of barriers and bodies need to be considered.

Critical realism concerns itself with the mechanisms by which social phenomena come into being. The theoretical stance is positioned at the junction between the natural and social worlds, and an area of focus is on the interaction between structure and agency. Any social phenomena are regarded to have three levels: the empirical level (at the top), which is the observed reality as interpreted by person(s), the real level (the base) which have the causal features that give rise to social phenomena, these are unobserved. In between these is the actual level (middle layer) which may or may not be observable. This level has dynamic aspects of how different competing causal features located at the real or even other aspects at the actual level may interact with each other.

The outcome of this interaction between levels is that they mitigate or enhance features that get expressed at the empirical level. Features of structure and agency and their interactions at the actual and real levels may well be unobservable and not open to human interpretation (Sayer, 2000) but can still be highly influential on what is observed. Fletcher (2016) has likened this structure to an iceberg with actual and real below the waterline.

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Figure 7 Fletcher's 2016 iceberg analogy for representing the structural features of critical realism. Iceberg metaphor of critical realism structure, showing the empirical, actual and real level taken from Fletcher (2016, p. 3)

With respect to matters of dyslexia-SpLD and inclusion within the context of education; what is observed, the empirical, about the nature of inclusion for children with dyslexia-SpLD can reasonably be deduced as the outcome of what occurs at the real and actual levels within the broader phenomena of formal education in England. A critical realist approach to inquiry therefore offers recognition that while the world may have structural features, it is also socially constructed. It offers a mechanism to identify both drivers of experience and the nature of the experience from both observed and hidden aspects. In turn this opens the possibility for the structural features and linked with agency to describe both the mechanism of impairments and the interaction with structures giving rise to disabilities.

Inclusion as a variable construct itself is a direct challenge to the accounts of impairments and disability. This is because it presumes that the application of inclusion will dissolve the phenomena of the barriers that construct disability (as opposed to impairment). Alternatively, or in addition, activity to secure inclusion may mitigate the impairment so that the barriers are no longer problematical.

Summarizing the landscape

Across the literature review there is a recurring narrative of children having difficulty acquiring one of the key fundamental sociocultural tools, that of written text-based literacy; one that mediates many of life chances and outcomes. It describes schools having difficulty meeting the needs of children with dyslexia-SpLD, both directly but also more widely in terms of their psychological, social and emotional needs. Finally, a recurring motif of parents endeavouring to ensure their children do access the basics of education, an enterprise that can result in accounts of distress and challenge. Linking all of these elements is the superstructure of presumed inclusion, and the perception of failures of inclusion to dissolve the educational impact of dyslexia-SpLD on the child, family, social and wider settings. Those impacts have been shown to extend beyond the school setting or mandatory time of attendance and permeate the child's life.

The research question

It is reasonable to conclude with a problem having a persistent history over decades and parents and children's experiences presenting across many nations in similar ways that there are likely to be common structural aspects and patterns of agency that create the observed reality. These two elements suggest that critical realism, which is focused upon such form of interaction, would be well positioned to explore the issues raised. Further, parents are located by the system as a part of it through providing support to the school and child, but also they are located outside it, in that they have no formal position within its structure. They therefore can offer a unique perspective on the enterprise of education. However, to date they have had limited contribution into this area. It is therefore worth engaging the one group who have long term knowledge of a child about what they see and understand of the school system, its application of inclusion and what they do to try and ensure their child can acquire the essential skills and social mores to join society as an adult. Finally, the research strategies adopted in much of the research work reviewed has provided an empirical description but not

fundamentally examined the drivers for the observed realities; so inquiry methods that can adopt the investigative stance of critical realism may be able to extend understanding and position proposed ways forward. Using crucial realism as a research orientation, a reasonable research question would be:

In what ways do parents of children with dyslexia-SpLD perceive, understand and enact inclusion.

In the next chapter the detail of how the inquiry was formulated, and the methodological description is laid out before considering the result of the study across 5 chapters focused upon different levels of analysis.

Chapter 3: Methods and Methodology

Introduction

The preceding literature review suggested that critical realism with its ontological and epistemological stance was an appropriate orientation to address the main research question.

This chapter will lay out how critical realism's position is transformed into the novel development of a new strategy for educational research of combining critical realism, case study and thematic analysis. The novel approach combines approaches and methods, which draw upon the tools of case study, interview (both individual and group) as well as survey. The work draws upon Easton (2010) and Sayer (1992, 2011) who in combination provide a comprehensive philosophical and epistemological framework that argues that such approaches should underpin social science research work and underpins this work. Sayer (1992) lays down the basic tenants of critical realism which he argues should shape research work.

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Figure 8 Key features and assumptions underpinning critical realism research methods

The description, of the ontological and epistemological orientation as well as the “emancipatory axiology” (Easton, 2010, p. 119) of critical realism lent itself well to examining complex systems that children and their parents with dyslexia-SpLD interface with, that the tried and tested methodologies had not been able to address. Fletcher (2016) extended the critical realism research framework to deal with complex systems and processes, by suggesting an orientation towards both meta and individual data, and of methods that made use of inductive and deductive stances so developing an understanding of how the individual was placed in context within a critical realism orientation. A case study approach as described by Easton (2010) (also drawing upon the work of Thomas (2011)) was used to provide a methodological framework within a critical realism positioning, which also allowed ethical considerations around anonymity and confidentiality to be applied whilst still maintaining the integrity of the research.

Critical realism, case study and research methods

The nature of inquiry and methodology

The methodological contested space that critical realism occupies is where causal attributes of fixed/stable universal features and the non-stable/non-fixed intersubjectivity interact. Consequently, there is complexity in how methodology and epistemology, which traditionally has focused on either fixed or flexible orientations, is applied. As Easton (2010 p122) notes critical realists “accept that the world is, of course, socially constructed but argue this is not entirely the case. They construe rather than construct the world. Reality kicks in at some point.” It recognises that structural features can be strong enough to overcome contextual features; but may also in reverse be constrained or overcome by agency or context in other circumstances. There is therefore a dynamic interface and tension.

An application of this within this study is from parents contesting allocated provision for their child with dyslexia-SpLD. The structural features of a local school/education system

(which is in turn located within a legal and policy framework), or a specific school leadership may through their decisions on resources negatively (or potentially positively) impact on a child or children with special educational needs including dyslexia-SpLD. However, negative power and influence can be constrained and overruled by an application of agency, for example by a parent who instigates another structural feature, the legal system, and its processes, which steps in to moderate the school, or administrative systems actions and stances. The observed outcome is of a child receiving additional support or specialist help in the school setting, additional to, or different from what was ordinarily available. However, below that empirical level of observation there were some contested forces, which simply by observing the child would not be seen. These contested forces could explain why two children with seemingly similar profiles with respect to the fundamentals of dyslexia-SpLD could have different presentations and trajectories as discussed by Carroll (2020) in her review of current understandings of SpLD for the Government Office for Science. So, the methodology of critical realism studies is concerned with bringing into visibility the mechanics of social phenomenon that are seen in the empirical world, and the inquiry methods used need to be able to address this feature.

The rationale for critical realism and case study methodology: a novel development

It is helpful to describe what methodological approaches were considered before arriving at the one selected for this study. To address a complex cognitive and social systems interface, mixed methods (Denscombe, 2008) was originally considered and explored. As an approach it allowed for multiple ontological and epistemological frameworks. It moved past the limitations of the singularity of qualitative or quantitative framing of inquiry, however it did not resolve the conflict and tension between them. Its focus was on the method and the rigour of findings and primarily provided a descriptive account of an issue oriented from different perspectives. Ultimately this tension had to be resolved by the reader.

In contrast, discursive approaches (Bryman & Burgess, 1994) and Interpretive Phenomenological Analysis (IPA) (Eatough et al., 2013) provide rich description and clarity of the orientation but in the case of discursive approaches the focus is upon the use of language as a performative tool. For this study while difficulties manifested in the social world, there was underlying impairment, a reality that was not well articulated using research stances focused upon how language was used to describe and position the difficulty. Conversely, IPA's focus upon the experiences at the interface of the internal and social worlds was approached from the individual perspectives; it was ideographic small scale and in-depth and did not allow for different levels and forms of data collection and also therefore analysis. It also presented an ethical dilemma, the study required in depth exploration of a person and therefore the risk of unintended identification or collateral harm to fragile individuals was higher. Additional limitations where it also did not address the substructure of impairment, the group level or the structural features and was primarily descriptive. The difficulty was that some high quality, rigorous, and substantial descriptive accounts have been produced (Leitão et al., 2017; Lithari, 2019; Macdonald, 2010; Riddick, 2010; Zambo, 2004) but they have not fundamentally changed the experiences of children/pupils/young persons and their families, and they have not provided mechanisms for change.

In essence such research has held a valuable mirror up to the problem of observed difficulty (Kirby, 2018) but left the audience to infer something must be done, without providing the mechanism. That foreshadowed a limitation of those approaches discussed above to be the engine of meaningful change. This limitation does contrast with the scientific approaches that have suggested through study findings, ways forward. Case study as a strategy did allow for several of the identified limitations pertinent to the proposed inquiry to be addressed and had potential for an orientation to change. In this respect the philosophical orientation of critical realism also was compatible with case study approaches (Easton, 2010) as well as the orientation of the researcher, with case study able provide a mechanism for

interacting ontology and epistemology with a methodology described in the literature (Thomas, 2011; Yin, 2018).

Studies using critical realism have made use of both bottom-up/inductive and top-down/deductive approaches with respect to data gathering, so its epistemology draws from both traditions of inquiry. The critical realism stance used to illustrate the methodology adopted by Fletcher's (2016) study of Canadian women's role in prairie farming, argued for a top-down approach. That was through the application of pre-existing categories constructed from meta-data sources of social and economic factors to be applied to narrative data. While she made use of meta quantitative data and policy to guide her enquiry, there is also evidence of inductive processes in how the qualitative data that shaped her study was handled. This suggests that rather than simple *a priori*, as claimed, Fletcher was acknowledging the lens with which she was approaching the qualitative work and was explicit about this.

Applying Fletcher's (2016) approach in the application of meta data with respect to this study, use has been made of English national data for example the material from the school census and assessment data. Its annual reporting and review of the meta data for English national data sets of pupil characteristics (Gov.UK, 2020b) of those in education provide an wider account of the nature of and how different groups perform on outcomes as discussed in the literature review. Thus, meta data provides some form of independent measured description which can be interrogated against narratives and other data collected for this study. This provided important contextual frameworks for this study.

Other studies focused on dyslexia-SpLD and inclusion from qualitative traditions have made use of stances that used bottom-up data; for example, using long standing principles associated with grounded, phenomenological and social justice research approaches (Charmaz et al. (2018)). Lithari (2019) and Riddick (2010) both explored the psychological and identity aspects of being 'a dyslexic pupil' and Macdonald (2010) and Deacon et al. (2020) examined

adults' perspectives on their lived experiences and schooling. Within these forms of qualitative inquiry, there is recognition of multiple realities, intersubjectivity and the significance of context and situatedness.

In contrast to experimental or most qualitative approaches, case study research makes use of multiple perspectives and epistemological lines of enquiry, in which depth of understanding is the research purpose. To achieve that it also engages in an iterative process between stages of the research journey (Verschuren, 2003, p 131-2), a process which draws down from the qualitative traditions but is somewhat in opposition to the quantitative ones. The iterative and critical stance features were prevalent throughout this inquiry (see appendix A and D and page 130), as the researcher sought to ensue authenticity of investigation.

In this respect the case study as a whole draws upon the themes of philosophical hermeneutics "which reject the idea that the rigour of research lies in following a method" (Hammersley, 2005, p6) and instead recognise that the purpose of a researcher is not simply to document other person's lives but rather to "deepen our own understanding" (Hammersley, 2005, p6). Such an approach recognises the presence of the researcher within the construction of the case, in the formulation of case study research.

This approach is consistent with the research undertaken for this thesis which is positioned with an insider view as a researcher. Firstly, one who had previously been both a governor at a school, but also has dyslexia-SpLD and with wider appreciation of how the profile is currently understood in education. The insider perspective allowed a unique form of engagement with participants who would have recognised and did respond to acknowledgement of shared knowledge. Sensitivity to the influence of personal experience on responding to or being shaped by the research process was a key consideration for maintaining rigour. To that extent at certain points, engagement with study data was suspended and alternative research activity was undertaken. Much of the integrated analysis of the data was

done throughout the study using extensive sections of writing. Those essays on a topic of relevance were then considered by supervisors and the basis of discussion. The supervisors themselves drew from a range of traditions and focus relevant to the study, and so contributed within both single and group discussions a depth of perspective. Sessions were then recorded and reflected upon. This allowed for assumptions and perspectives to be challenged or clarified and enabled a critical stance and the researcher position to be anchored, and rigour to be maintained.

From an education perspective there has been a promotion of evidence-based approaches (cf Davis 2018) generally being taken to mean quantitative research evidence, in which interventions are decontextualized. Thomas (2016) challenged the dominant narrative around what constitutes good research, drawing on a wide range of evidence disputing the notion of a universal gold standard such as randomised control trial (RCT). Davis (2018), using the example of Direct Instruction teaching, demonstrated such research had many limitations in application. Specifically, Thomas (2016) argues education research requires a plurality of tools to engage in effective inquiry, including among the tool box, case study research; which Yin (2018) argued is well positioned to answer how and why questions, but is not limited to them.

Case Study Typology and application to this study

The plurality about what constitutes case study research has led to confusion surrounding its merits and capacity to contribute meaningfully to knowledge production (Massaro et al., 2019). To address this, Thomas (2011) provided a framework or typology in which different forms of case studies could be located and their position articulated. This typology included several layers/classifications which could guide proposed structure and evaluation for case studies. The various layers included: subject, object, purpose, approach,

and process feature as illustrated below:

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Figure 9 Illustration from Thomas (2011, p.518.) "Fig 1. A typology of a case study"

A reasonable argument is that in addition to following Yin's (2018) suggestions of maintaining a critical stance, rigour of a case study could potentially be improved if multiple pathways and sub-case study constructions were used, thus allowing for depth/density of investigation from different sources to be consolidated. Indeed, this is the approach applied in this inquiry which is a series of groups (or mini case studies) constituting a whole. This approach would also accord with Easton (2010) who suggests a compatibility between critical realism and case study, both being orientated to "understand why things are as they are" (Easton, 2010, p. 119). However, to do this, it is by seeking to move beyond interpretive stances alone, by considering notions/explanation of pragmatic causality; through examining relationships between the observed/empirical world, and what are the plausible causalities that led to the observed.

The nature of case study research and its relevance to this study

Case studies, as described by Thomas (2011), are circumscribed research, having a unitary construction, the 'subject' of the case study which is of itself a source of interest rather than an exemplar of wider group. In this thesis, this is groups of parents and school staff. The subject (the participants) is operationalised through the specific focus of enquiry - a study of..., (the 'object' of the case study) which is the analytical pivot through which the research is constructed. For the case studies in this inquiry, it is 'inclusion' considered from a critical realist

position. It is the combination of object and subject that creates the necessary and sufficient features for a case study in research, but implicitly this is oriented from the researcher's viewpoint.

Massaro et al. (2019) noted that Case Study research has been variously described as a method, methodology and approach by different researchers suggesting a lack of coherence about what it offers to research; or how it is located within ontological and epistemological frameworks researchers access to conduct their studies. Massaro et al. (2019) undertook a study examining this aspect of coherence. They did this through evaluating the degree of conformity in application of method/methodology in the construction of case study research, critically reviewing relevant peer reviewed literature across 16 journals for their field, management and accounting for 2010-14. This comparison was relative to the research framework cited as the source in the study (Yin's classic texts on case study research work covering the period 1984-2014). The consistent findings of poor fidelity of application of Yin's framework and approach, despite having claimed it was the authority of the design was significant. Massaro et al. (2019) did not directly challenge the quality of the individual studies in their analysis; rather they confined themselves to the examination of the application of citations of Yin's work within each piece of literature. What they highlight is the degree of methodological confusion that precedes an inconsistency and lack of research clarity around trustworthiness of inquiry, which can lead to findings being challenged or having low rigour and reliability. The need to be transparent and explicit through all stages of the process was a key recommendation. The advice has sought to be applied in this case.

Yin's work covering the periods 1984-2014 takes a positivist stance with respect to case study, but in his more recent work, Yin (2018, p16) has somewhat tentatively acknowledged that case study can be used with both relativist and interpretivist stances. He suggests that the methods described in his text may not meet the needs of case study

researchers not taking a realist approach, but that they may still be useful material to access for such interpretive or constructivist studies. Within this study the overall approach of taking a critical stance articulated by Yin (2018) and specifically the notion of examining plausible rival explanations and rating engagement with them is of particular use (Yin, 2018, p232-233). Some of that work was achieved through the supervision process as described previously. Accordingly, due to the orientation of this work anchored in critical realism, while Yin's work has informed understanding of case study processes, it is the works of Thomas (2011), Easton (2010), and also Flyvbjerg's (2006) critique of the common criticisms directed at the use of case study that has shaped the work. All three authors have described approaches or features that allow for both constructivist and critical realist orientations to be adopted in case study research.

Case study by its structure allows a synthesis between the ontology and epistemology of critical realism and the traditional methodological stance underpinning established methods such as: interview, survey and observation. The case study research strategy has been used within an educational framework over recent years, with notable work around its use and development by Simons (2009) and Thomas (2011). The latter author was specifically interested in inclusion and education. The work of critical realism in education has also been developed by Shipway (2010). Easton (2010) did examine case study and critical realism, but it was in the context of marketing and management, not education. The lack of research using this combined modality may be because critical realism literature is more limited within the overall context of research published and it has two branches and philosophical focus leaders Bhaskar and Archer (Archer et al., 1998). It has only a fringe presence in educational research literature. Further, a reasonable argument could be made that the core texts are challenging to engage with for novice researchers, and for the consumers of research information. Nor do the processes suggest quick time limited studies. Nevertheless, the more accessible

approaches have not yielded effective answers translated into changed outcomes, so an alternative inquiry and knowledge production stance needed to be developed and explored.

Despite the novelty of this approach, the combination of a case study strategy and a critical realism stance is an ideal one. It allows for the exploration of features of the two groups that interface; schools and parents, by considering the structural and agency features that underpin and give rise to the observed realities for both groups. As such it represents an important research standpoint for difficult problems in complex systems, particularly since other approaches have been unable to resolve real world application. This advanced approach of melding critical realism with other approaches has been used in limited other studies such as Hood (2015), who looked at the issue of complexity in child protection using Interpretive Phenomenological Analysis (IPA) and Critical Discourse Analysis within a critical realism framework. However, this kind of strategy on a narrow segment and sample did not enable the research question for this study to be examined.

All this suggests that while the wider picture can draw from meta data and draw from the metrics orientation that is prevalent in education, the approach of building inquiry from bottom up is needed to understand the gaps. Principally, to avoid the pitfall of ignoring salient information, such as parental knowledge, which may silently mediate the observed and experienced reality of children with dyslexia-SpLD in their educational journey. Critical realism and case study offer in combination a means to identify potential causal features that have constrained good outcomes for children and effective inquiry into those outcomes to date.

Case Study in this inquiry

Overview of case study

The child with dyslexia-SpLD is in part located by the contested interface between school and parents, and their associated views on inclusion and learning. While the business and work of schools has been well represented in the literature, parents and the business and

work of being a parent advocate for their child and inclusion had not been. This is a gap which has not been well documented over time with a limitation on published literature. Leitão et al. (2017) from an Australian perspective and Lithari (2019) from a British one have provided two accounts of, young person/ parent/adult perspectives; while others have been discussed in the literature review (for example see page 74). While both had drawn upon thematic analysis which this study has too, neither Leitão et al. (2017) nor Lithari (2019) had taken a case study approach. Instead they had adopted approaches anchored in specific theoretical orientations; in Leitão et al. (2017) an ecological stance drawn from the critical ecological model of Bronfenbrenner and in Lithari (2019) symbolic interactionism. Both apply and expand or test theory, rather than generating new conceptual frameworks which critical realism explored with the use of case study would allow.

An important contribution to the field is to illuminate the drivers for what is observed in the empirical world of both groups and to develop a conceptual framework that could be used for further inquiry. The focus however was on parents as they were underrepresented in the literature. The school case was used to provide an alternative account in order to illuminate and consider the context of the systems and structure using insider viewpoints. While a small number of doctoral studies around dyslexia-SpLD have explored the school-parent-child axis, they have been very small scale and have not been published in peer reviewed journals. Other studies have considered the parent and child perspective. Leitão et al. (2017) and Lithari (2019) did also call upon one expert education professional to represent the school perspective. While that had been used to indicate a counterpoint, it is doubtful that any individual could represent an array of school's perspectives. There has not been any study identified that focused upon dyslexia or SpLD that gathered from a range of sectors, the perspectives of parents and school staff and considered them as a group or groups, individually, together, and in combination, to draw upon a rounded account of the field.

Constitution of case studies

Five subgroups of different participants were assembled that were engaged using a range of methods of data collection (see page 121, page 124 and Figure 11). This allowed for broad representation across the area of inquiry reflecting from the literature some of the important known factors of influence. The group were not a representative sample, rather they were a functional sample with an array of relevant (but not comprehensive) diversity. A notable gap in the diversity range was limitations of fair representation of heritage-cultural diversity. That gap occurred both for lack of accessibility/ ethical issues and practical reasons around running a solo project. This addressed in the future directions section (p331).

However, the key indicators of socio-economic profile of individual and locality, gender, degree of dyslexia-SpLD difficulty and complexities, type of education setting, and family profile were included. As the study progressed across time, greater diversity was constructed into the case studies. An iterative process of issues and findings from each subgroup informed the development of future analysis and recruitment. That in turn re-informed the analysis of the original study data. This was an important part of the development of each of the parent and school cases. Data was captured in two phases four years apart, each phase had a slightly different focus. The first was capturing and describing the landscape of the field of inquiry. The second, emerging from the first, explored inclusion and dyslexia-SpLD. This reflects a temporal dimension to the case studies reflecting Thomas's (2011) typology and framework. Comparing the construct of the case studies and subcase studies with Thomas's framework it can be seen a range of case study forms have been drawn up which notionally contribute to increased rigor (see figure below).

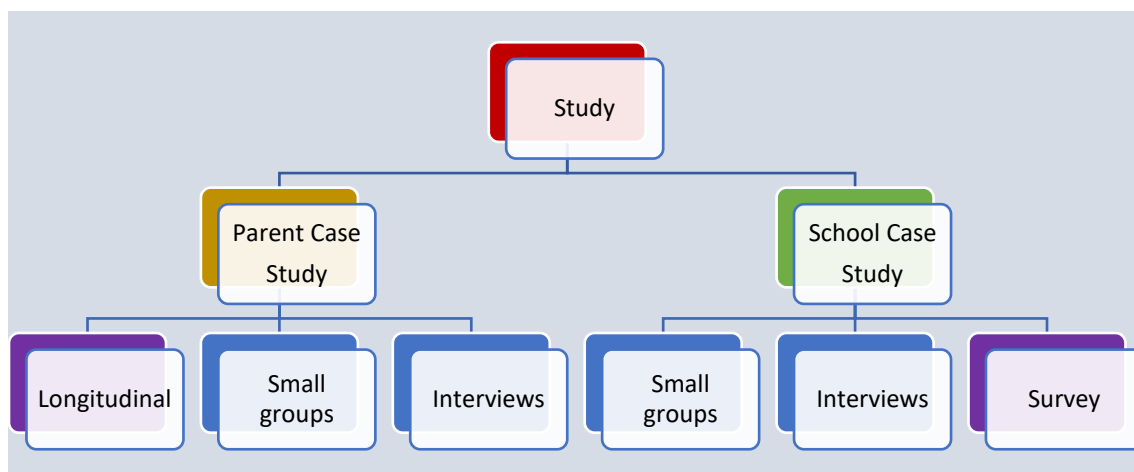


Figure 10 Structure and components of sub case studies constituting the two principal case studies of the thesis illustrating phase 1 (purple) and phase 2 (blue) of data gathering

Research methods and approaches

Critical realism is involved in both theory-building and theory-testing as part of the iterative process to identify its version of causality (Fletcher, 2016). This stance has sympathy with and can link with case study approaches, which are driven by having an in-depth understanding of a case, however that is defined. To do the work in this study from a critical realism stance, there are three core features that need to be addressed from a methodological perspective and a fourth in securing understanding for it to be an effective critical realist study.

These are firstly, the use of demi-regularities, which are patterns of occurrences within the data.

Secondly, abduction, which can be thought of simplistically as the researcher being a critical scientific detective and understanding the evidence. Abduction is also about researcher engagement with data, not coming within the original theoretical frame. Therefore, the approach/ method must allow for flexibility.

Thirdly, linked to abduction is retroduction - using the evidence to find the solution or explanation. From a research perspective that is a process of looking back, and through this identifying the situation or circumstances that are thought from the options available to be

essential to the subject of enquiry; without which it would not come into being or endure. Retroduction has been described by Sayer (1992, p. 107) “as a mode of inference in which events are explained by postulating and identifying mechanisms which are capable of producing them” and can be thought of as best fit explanation. The main risk here is drawing false inferences, so a critical stance is a key component of retroduction.

Examples of the core questions in this analytical framework could be: what data falls out of the given or assumed theoretical framework of inclusion for children with dyslexia-SpLD, but is important in some way for understanding it? Or what are the necessary and sufficient features in education required for inclusion to occur? In each case it is the presence of demi-regularities that provides important evidence to explore those features of abduction and retroduction and examine the mechanisms or deep processes which gave rise to events. These three features can be operationalised through the case study format.

The fourth strategy was to consciously consider what Yin (2018, p xxii, 233, 245-6) referred to as “plausible rivals” to any explanation or conclusion. This works alongside retroduction and is about considering how multiple potential explanations are evaluated; the evaluation occurs through taking a critical stance on the evidence and any assumptions. In this study the role of the supervisory team was important in exploring plausible rivals in allowing ideas to be tested and deconstructed. The sessions were recorded so they could be reviewed, in effect as objects of analysis.

The following section examines in more detail three structural features of the study: the use of case study, interview, and survey.

Data Collection and organisation

This section deals with the principle original data collection and the sequence/time frame of the research project. It then lays out approaches and theoretical framework for the structure of using two case studies, tools of interview and survey used in this study. It starts by

considering the key organisational structure of case study and how the subsets of the two case studies were constructed before looking in some detail at ‘interview’ and ‘survey’. However, to provide a framework to ease understanding of the formation of the case studies the timeline of data collection is graphically illustrated below.

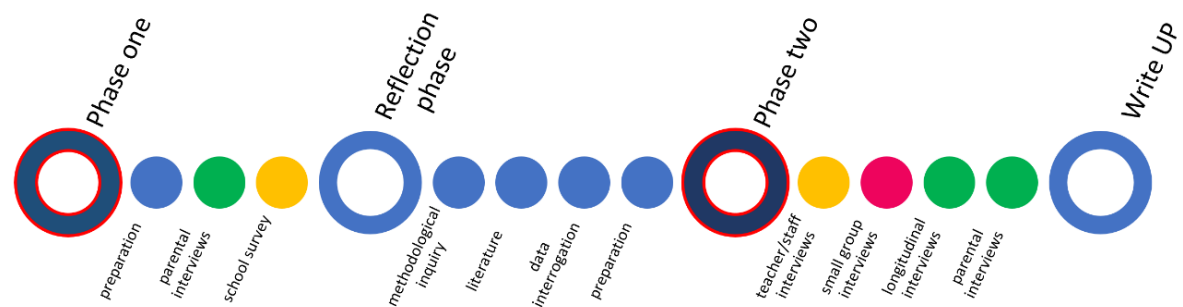


Figure 11 Graphic illustration of relationships of components of the study across time: blue is researcher focused work, green is parental case study, amber school case study and pink provides to both case studies. The two data collection phases are marked by red outlined rings.

Data was collected in two phases (referenced as phase one and phase two), each phase serving a different purpose. Each phase was located by initial preparation for entry to the fields e.g. securing ethics and developing initial research questions. Then by subsequent pre-entry to field work, including further ethics and developing research questions. Finally then bounded by the terminal analysis and write up. The write up process forming an important part of the analysis.

Link between typology and this inquiry

Literature, such as Flyvbjerg (2006) and Yin (2018), suggest that the construction of case studies is purposeful and forward planned. In contrast Verschuren (2003) and Thomas (2011) suggest an evolving process. This study is unusual in that it tracks the evolution of the researcher’s questions originating from an observational and moral puzzle and an orientation towards mixed methods into a fully formed case study research inquiry (see appendices A, B and D). In doing so it illustrates both the spiral nature of enquiry and the iterative processes

that are engaged to develop meaningful research. To the extent that what is described in this study reflects an organic process consistent with the grounded approach as described by Charmaz et al. (2018), it is positioned differently from other forms of positivist orientated case study as described by Yin (2018). The typology provides a classification system which positions studies within an intellectual and practice framework allowing for both clarity about what has been covered and highlighting gaps. It also creates an effective description of the boundaries and limitations impacting upon claims that follow from this inquiry.

Critical issues in the development and application of research tools

The research tools used in this study were: desked based research such as access to public government data for example relating to schools, pupils, and their characteristics (e.g. Gov.UK, 2020a, 2020b); interviews both singular and small group; and a survey exploring inclusion which was conducted by the author for a school but was imported into the study as secondary data. The data was therefore both meta data and specific qualitative, with the focus on the material gathered directly for this study.

Outsider and insider perspectives

Across the literature review a great deal of attention had been placed upon research and theories that took up an outsider perspective. Very often it was adults, observing other adults doing things to children. This also included the orientation of the grand theories of Bronfenbrenner's bioecological systems theory (Bronfenbrenner & Ceci, 1994; Shelton, 2019) and Engle's biopsychosocial theory (Borrell-Carrió et al., 2004), neither addressed the insider viewpoint. In that respect much of the work addressed in the literature review adopted the observer stances from the scientific community. Other qualitative work, for example Riddick (Riddick, 1996, 2010) and Macdonald (S. Macdonald, 2009b), Deacon et al. (2020) and Johnson (1985) did capture insider perspectives and as discussed these provided important experiential

accounts. However, while they laid out the wider consequences of dyslexia-SpLD they did not directly identify mechanisms that gave rise to the experiences, rather they left inference to the reader.

This study sought to gain insider views, and for the participants to be both observers of self and others, and sources of/for observation by the researcher, but the aim was to move beyond description and to understand or identify mechanisms of causality. To do that there was a need to identify constructs that were open to examination and evaluation and ones that could be subject to challenge and change.

The collection and processing of the data in the study draws upon ideas explored in Kelly's personal construct theory (Kelly, 2017) originally published in 1955. His work focused upon the way people make judgements using bipolar comparisons and in doing so reveal the constructs underpinning such judgments. He developed tools such as the repertory grid to apply the work of personal constructs as part of therapy in a clinical setting. Information from patient or participant was structured to systematically gather a sequence of comparisons, each between two people selected from the respondent's direct community. In this way identifying the core constructs an individual uses to make judgments about self and others and use that information to help people understand their value system and examine its impact.

In a similar manner across the data collection there was an embedded pattern of either participants or me making comparisons around persons or situations to gain understanding of what was shared or different, and so illuminate the conceptual structural features. In the following example three questions were posed in an interview with Karen to illuminate the features and construct of inclusion. These questions then went on to deliver information that became central to understanding how inclusion was constructed and destructed

I: So, what are the features of teachers that do adapt to the needs, versus the ones that don't adapt?

I: [...] Okay, let's go and look at perhaps ones where it doesn't work. What are the features of that?

I: Okay. So, if we think about a broader question, what would inclusion for you look like in a school? What would really good inclusion look like?

In relation to the last question this has similarities to work of Strachan and Jones (1982) who used the strategy of the repertory grid to evaluate how young adult's judgments shift across age groups, but also considered from the data how people have both an idealised self and an actual self. In this study by asking most of the participants in phase two of data collection what their idealised version of inclusion was, it was possible to draw upon that to frame other parts of their account, and gain understanding of the gap between expectation and reality for them.

From the answers provided and other elements that Karen described it was possible to abstract the aspects that were valued by Karen and so through repeating that process across the data also identify the demi-regularities and contrasts across the data sets. However, unlike the repertory grid the data collection was not highly structured and consistent; it was a strategy utilised within the context of interviews and gathering survey data, it fitted well with the analytic strategy and the stance of critical realism, within a thematic analytical framework.

Interview

This is the principal tool for data collection in this inquiry, so is described in some detail. In the study there were two forms of interview used, both semi structured one-on-one (individual) and small group. The difference between them was the degree or weight of activity of the researcher in setting and the way the threads of conversation are developed and maintained between people. Interviews, as Brinkmann (2018) notes, are a structured form of conversation, an established mechanism for gathering human accounts; but such information

is complex and typically comprises of not one unitary voice from the speaker but often are polyvocal accounts with inherent contradictions (Brinkmann 2018 p581). In the study it was observed how participants would take on the voice of another, their child. For example: he **“kept saying mum I can’t... why can’t I read?”** (Nora). Sometimes they replayed a mini scene of a conversation, as per example of Beth between her and her son’s teachers: **“I said: ‘he’s not lazy, he has a difficulty’. ‘No, no I think you’ll find Bob’s just lazy’”**. Archer (2000) in her work highlights that conversations occur not just in the empirical domain when things are seen and heard, but also happen internally, self-structured and usually hidden from view, but on occasions may be partially inferred or obliquely accessible to others.

However, more recent work adds an additional dimension to the construct of interview when consideration is given to the presentation of self (cf Dunning, Helzer and Dunning 2012), work that suggests that people have at best only partial knowledge of the self (and from studies it can be a misplaced understanding), but also people can display wisdom about others, who in turn can see aspects of the self, hidden from personal insight. This complexity has implications for the use of the interview in research, both in the collection of data, its impact on both participant and researcher, and in its interpretation. Despite the challenges in use, they are an essential part of a toolkit of established methods in research.

Architecture and typology of interviews

The term interview comes with several assumptions around the relative balance of power and contribution within the exchange (Qu and Dumay 2011). From a research perspective, the work of Alvesson (2003) is helpful in providing a description of interview as a spectrum and with an associated typology for qualitative work. Firstly, there is recognition that the stance of the researcher and the purpose of the research plays a pivotal role in how the architecture of the interview is constructed. Interviews are also social relationships that come with expectations of behaviours, social scripts and the types of way the utterances are

constructed between people as noted by Brinkmann (2018). From a research perspective utterance is either verbal, sub-verbal, non-verbal or textual form.

Within the spectrum of interview, three positions are identified by Alvesson (2003) neopositivist, localism and romanticist. Which reflects the degree to which the interview is sharing a factual or experiential frame. Located between the poles is the localism interview, which recognises the importance of social context and intersubjectivity for any material generated from the interaction. The central tenet is “social phenomena do not exist independently of people’s understandings of them, and that those understandings play a crucial generative role” (Hammersley, 2007, p. 297). Such interviews are also regarded as empirical, in the manner other activities can be actioned or observed, and as one of many ways of being in the world. This positions the localism interview as a human activity, one of many human activities rather than something special. However, there is also the dimension of ‘time’ in relation to events (being commented on) and to interviews; and how the person is positioned within their history and memory of it. The passage of time, the salience and impact of the events have a role in how they are captured for the person. Memory can be fallible or exceptionally clear within circumscribed boundaries but as Easton (2010 p123) notes “The events can be recorded live or exist in records of the past including the memories of those human actors who can attest to the events”. With this framing, the orientation to a form of localism interview was adopted and the positivist elements were backgrounded.

Constructing a stance for interviews within a critical realism framework

With a lack of referenced sources addressing this matter from a critical realism and case study perspective, there was a necessity for the researcher to construct her own position drawing from the literature described above, and experience. Interviews were constructed in as open a manner as possible within the context of each interview or small group and phase of enquiry. They were positioned as localism ones recognising the polyvocal nature of exchanges.

The contribution of insider knowledge to interviews

The researcher had insider knowledge through self and family experience. This shaped the dynamic of the interview and the capacity to appreciate points being made by either parents or teachers and to follow up and probe as relevant. For parents understanding how education can be viewed as a process of plotting pathways and future stories with reference to past and present, rather than just the current position was helpful. That was a salient aspect for the parental interviews, but also reflected in some of the school staff ones. For the staff interviews prior experience and knowledge of school operations and challenges were also important. The quality of information gathered was contingent upon the participants being engaged effectively in that interview (or indeed survey) and to that end it was important that those engaged recognised the researcher had insider knowledge, was authentic and could access familiar narrative, and was regarded as trustworthy.

Time frames of research process for parental interviews

Phase 1 had subgroups 1&2, phase two had subgroups 3-6. The six subgroups were consolidated into two core case studies, a parents' one, and a school one, with one small teacher and parent group contributing to both case studies.

Table 1 Components and contribution of Parent and School Case Study

| Subgroup | Who involved and the focus of data collection and type of recruitment |
|----------|--|
| 1 | 6 participants: parent in-depth interview; primary school stage. Initial study group open inquiry recruitment was purposeful. |
| 2 | 34 participants: Single-school staff & leaders survey focused on inclusion, primary school with 34 Participants. Follow on drawing information from group 1 (secondary data) |
| GAP | Period of data processing, reflection and alternative supportive work (3 plus year gap) |
| 3 | 4 participants: Follow up to original parent in-depth interview, secondary school stage. This subgroup of 4 from group 1 formed a longitudinal study group. Also included a focus of dyslexia-SpLD and inclusion. Recruitment was purposeful. |
| 4 | Small group of 3 teachers and 1 parent from one school exploring the practice and understanding of dyslexia-SpLD and inclusion. This drew from phase 1 and the other interviews in phase two. Snowball recruitment |
| 5 | 17 (11 active) participants; General staff interviews, inclusion, and dyslexia-SpLD; primary and secondary school stages draws from survey and phase one interviews. Included TA group interview & individual interviews with teachers. Snowball recruitment |
| 6 | 12 participants - parental interviews focused on inclusion and dyslexia-SpLD, primary and secondary school stages. Draws resources and information from phase one interviews and group 3, 5 and 6 information. Snowball recruitment |

The research had evolved across time with an iterative process of engagement with data, literature, research activity, personal learning and reflection; leading to greater understanding, thus shaping the architecture of the interviews as they progressed. The development of the interviews can be seen across the interview schedules in appendix B and is outlined in the method section below. Broadly the opening interviews took a historical stance of what was seen and what had happened. The survey explored different understandings of inclusion using Göransson and Nilholm (2014) as the framework; the interviews for phase two explored people's perceptions, understanding and associated enactment around inclusion and dyslexia-SpLD within the context of their history or experience.

Location of interviews relative to legislative framework

Phase one interviews took place at the transition point from the end of previous legislative framework which concluded September 2014 while the survey was in the early months of the new framework. Significant changes to the law governing education and special educational needs and disability were incorporated into the legislation in England which had become established with the Children and Families Act 2014 (GOV.UK, 2014) and

the associated legal guidance, the Special Educational Needs and Disability Code of Practice :0-25 (Department for Education, 2015). Specifically, there was an explicit orientation to 'inclusion', and the code of practice incorporated much of the prior case law which had been muted and legally implicit. It was both relevant and appropriate to capture current perceptions and experience three years after the change had come into force (phase two of this research), to see if there had been any marked differences in practice or application and to address the new orientation. The combination of data captured in the interviews across both phases was both extensive and focused (Sayer, 2010) which allows for depth of analysis.

Environment in which interviews were conducted.

With respect to environmental context, in phase one (including the survey), the participants who were interviewed/surveyed were engaged in the setting in which they made decisions and encountered consequences, perceptions and experience of inclusion policy. For the phase one interview this was the participants' own homes, for the survey it was the school premises. Later in phase two, the option of interviewing parents in their own homes had changed with Coventry University ethics regulations. While it was still possible to interview school staff in school as a public place if that's what they wanted, and some chose to meet in the community instead, parents were interviewed in public settings that had social familiarity for them.

For the parent small group they were interviewed in the shared common publicly accessible space they were familiar with. Those interviews had a different slant as the group discussed matters between themselves as well as with the researcher so different forms of information were elicited. Prior to all interviews starting, and following ethical approval requirements, formal consent procedures were implemented. All interviews were digitally recorded, which then left the interviewer to be able to fully focus on the interviewee and the interaction. Following the interview, the recordings were secured on university secure servers,

a process of familiarisation of content took place and interviews were professionally transcribed, then anonymised. That process adding an additional form of familiarisation, before being loaded up into NVivo on a password protected computer.

Thought was given to how questions were developed and following initial development, these were discussed with the supervisor team. They were reviewed by one informed parent who was not going to be a participant but had good knowledge of the SEND/dyslexia-SpLD parental experience.

Types of questions asked in interviews

Phase one

For the phase one interviews there were 6 guiding topics that assisted in eliciting a structured historical account for each of the parent participants. These drew from prior experience of conducting clinical interviews in the health field. A temporal based history of events from the participant's position and recall guided by time frames provides a predictable way for the participant to navigate the shape of the interview. The pattern of questions was shared at the start of the interview. Three themes linked to gaps in the literature were important, what had happened, what had the parents seen to prompt action, and how did they interpret the information they secured. A sample of the key questions from participant 12's interview is used to illustrate the point.

- a) Would you'd mind sharing your memories of his early years, leading up to when he started school.
- b) Could tell me about the early education, sort of, up to and in Key Stage 1?
- c) So, we're starting in juniors at that point. So where was (name) when he transferred into Year 3? How was he at that stage?
- d) What happened next? What was the evidence that you used, that told you actually there was a problem?
- e) If you were to suggest things that needed to change, (because the purpose of this is to identify how things need to operate differently), what would you say would be important?
- f) If you had a chance to communicate your learning, what would you want other parents, the school and the authorities to understand, do more of, or do differently?

Figure 12 Sample of interview questions taken from participant 12's interview in phase one.

Phase two

For phase two similar orientation was taken but the questions were less structured and more open and were positioned towards the romanticized end of the localism interview, in that thoughts and feelings and contradictory interpretations and experiences were privileged. There was a focus on the participant's child and their accounts of the child and how they perceived and understood inclusion and dyslexia-SpLD for them. The opening question for each parent in the non-longitudinal interview group in phase two was anchored with this perspective and was about asking participants to share their story and then following up with what they said. For example in the parent case the first question to Susan was **"So tell me a little bit about Sarah's story"**, the next open question, after the follow ups, was to gather views on inclusion: **"I would be interested to know what you think inclusion is or should look like? When you hear the word inclusion what it means?"** The schedule (in appendix B) was flexible enough to pick up on points that emerged from the interviews. In the following example two of three [participants 8 & 9] declared in the interview they had dyslexia-SpLD, but one had not declared to her employer [participant 8], a third did not have it, so the question naturally arose of the two that did have dyslexia-SpLD.

Both of you have described difficulties that extended into adulthood and both of you have described the way you've developed compensation. You've said [participant 8] you don't declare, you said you're using your strength. [Participants 8 and 9] How much of your drive for your kids was kind of driven a little bit by actually knowing how hard it had been for you?

The conversation then explored the contrasted the motivations with the participant [10] who did not have dyslexia-SpLD.

Interviews also involved the researcher reflecting back the account being given as in this example when I responded about Peter's difficult in reading: **"That must have been really disheartening for him"**. Or recognising shared experiences, in this case Penny's frustration as an adult dyslexic remembering school days: **"I: Yeah, yeah join the gang."**

For the longitudinal interviews the initial focus was to recap the story from the last meeting and then explore how the types of support were perceived to have made impact and how they and their child were understanding inclusion since that initial interview. This followed the central form of the localism form of interview. The following sample of questions are from participant 6's phase two interview as their child approached the end of his school education and looked to move onto post-16 college placement. It was an opportunity to also see if the legislation had made any practical difference from the parental perspective.

- a) Could we just look at what's happened over that last four years, how education has gone, what your thoughts and aspirations were, what were the things you ran into, success or difficulty with?
- b) How have you seen his dyslexia profile difficulties with reading, writing, spelling, how's that changed over the four years? Has it changed much?
- c) So, if you're looking at his notion of inclusion, are you starting to hint of the idea of the continuity between what happens in school and what happens outside, and presumably to do some of the things he wants to do, he needs to get his maths and English, is that about right?
- d) Yes. It sounds like from an educational bit, it sounds like he made progress; what impact do you think the statement had in terms of getting him to make progress?
- e) One of the ideas is that inclusion has all of the kids, all ranges and abilities in the same class, and listening to what you're saying, it doesn't sound that actually from [names] side that works particularly well for him. I'm just wondering what your thoughts are around what good inclusion for <name> looks like?
- f) There's a big shift in the legislation about the role of parents, but I'm just wondering if you've seen any difference at all from when we started using the old system, to this one?
- g) If you look back now, and this is almost the same kind of question that I asked at the end of the last one, and you have a chance to communicate what you've learnt, you're looking back right across his education, what would you want parents, the school, and authorities to understand, or do more, or do differently?

Figure 13 Sample of key questions used for participant 6 in their phase two (longitudinal) interview.

The questions for school staff in phase two

For the teacher interviews the focus was on gathering their understanding and perspectives around dyslexia-SpLD and inclusion. The questions developed drew upon knowledge from experience and roles and the issues raised in the school survey, but also on the information provided in the parental interviews, again the schedule allowed for flexibility to respond to content. These questions while still localism interviews took on a more slightly neopositivist orientation, which was sympathetic to the professional position the participants were in. They were still of an open configuration, but they drew on the idea of objective shared reality. The questions were around gaining an account of their understanding, the size and nature of the problem as they perceived it and how they positioned the contribution of

the family and the system into how the problems they faced manifested. The sample of interview questions are taken from Hannah's, a SENCO in an urban high school.

- a) I just wanted to start by considering the topic of inclusion and I wondered whether you would mind telling me what your understanding of inclusion is, or how you would define or describe it?
- b) But I was wondering, having had the description of inclusion, what is your understanding about dyslexia specific learning difficulties?
- c) So, if we look at children with dyslexia, about how many do you think you might have who have diagnosed or undiagnosed but suspicions, of children with literacy specific learning difficulties?
- d) For children who have dyslexia, how does inclusion work for them, in reality? So what are the issues?
- e) So, when you have children who have these additional needs and staff require time but haven't got it, what happens to the staff, and what happens to the children?
- f) So, thinking about the children you have taught who have dyslexia specific learning difficulties, what needs did they have and how did you address their needs and what were the outcomes?
- g) So, I'm going to go back now and ask another question, which is about inclusion. You described inclusion and you described it in terms of the child processing forward. How does inclusion work for the staff?
- h) All of this is following on from this conversation we've had okay, if you had no recourse limits, what would inclusion look like for children with dyslexia? The idealised version.
- i) How you see the contribution of family to effective educational management for the child with dyslexia.
- j) I suppose the question which follows on from this is, is there a point fairly early where it needs to say actually mainstream can't cope with these kids because the trajectory isn't going to be successful to them?
- k) What makes it difficult for a child with dyslexia to have inclusion in that setting?
- l) Is there anything else you'd like to add about the broad area of inclusion in dyslexia and education, anything you'd like to add or clarify?

Figure 14 Sample of questions from teacher interview with Hannah in phase two

Survey

Introduction

Like the term 'interview' which initially appears to be widely and commonly understood as one person asking questions of another, but has many facets and dimensions, the term survey is equally as complex and potentially misunderstood. Surveys appear to be a

strategy to gain a wide body of information easily, but this would be a misleading assumption and in this section the key issues around survey will be highlighted. Giles (2002 p99) notes that the term survey is contested, around for example, size, frequency, and what the difference was between questionnaire and survey and other factors. However, Giles (2002) does identify two basic types which are temporally located, longitudinal and cross-sectional. In this study the survey was cross-sectional. Unusually it captured most of the target population, rather than just a sub-sample, so provided greater depth of information for that setting. The principal role of the survey in this study was to act as a counter narrative through the providing of a whole school account in which to test broader parental perceptions. It formed an important function of providing an in-depth understanding of inclusion from a single school perspective, one that was predisposed towards inclusion.

Issues of sensitivity and improving response

An important point in the survey approach is the degree, irrespective of the type, to which the survey can represent the population sampled to enable conclusions to be drawn from the data. In this case the population was the school (not schools or teachers). One way of improving responsiveness for sensitive topics is to make the survey fully anonymous. Such surveys have limitations around the detail of participant, that realistically constrain effective inquiry as noted by Murdoch et al. (2014), but they also found they were useful for dealing with sensitive information otherwise difficult to access. Views on inclusion would constitute a sensitive topic.

Matters of simplification in survey design

Another consideration is the impact of simplification required in survey design to facilitate analytical frameworks, and the degree to which that limits knowledge. Quantitative approaches need clear pre-existing, commonly understood, mutually exclusive categories. Surveys dealing with complex social issues face difficulty in gaining depth though the inherently reductive nature of their design but do offer a way of securing information that may

be difficult to elicit in face-to-face interactions. Further difficulties can arise due to inability of respondents to seek clarification to questions they may have. Schaeffer and Presser (2003) drew attention to the multiple cognitive demands of information processing required to answer even relatively straightforward questions in a survey, while Iarossi (2005) provides a comprehensive review of survey method in his book and notes the challenges in both design and delivery. One of the problems around securing the authentic voice of participants, particularly around sensitive topics, as implied by Murdoch et al. (2014) in their examination of the factors in survey research, influencing participants' degrees of disclosure of sensitive information. Public views on inclusion from professional staff would fall into that sensitive category.

From the early work on inclusion and education in the United Kingdom (cf Dyson et al., 1994), the limitations of paper-based questionnaire /surveys where handwriting is exposed, and which include assumptions about what terms such as inclusion meant to respondents, were noted. Later work by Farrell et al. (2007) used observation, interview and document analysis, which could be regarded as a physical form of survey, as described by Giles (2002). However, such data collection strategies do involve 'public faces' of participants regardless of if they are paper based or person-to-person. Consequently, creating greater or less degrees of authentic voice, which may have been a factor in the mixed messages that arose and the contested value around inclusion research (see Dyson, 2014). This is a sound example of how a research process can have much wider implications including potentially misdirecting policy.

With respect to this study the anonymous survey offered one important advantage over public survey strategies such as observation or accessible to view handwritten questionnaires; namely people were able to answer questions as they saw fit. They could do so without any pressure of social compliance; a feature noted in the work of Murdoch et al.

(2014) on gathering sensitive information. Given the positive social pressure in education on accepting inclusion as a good thing, being able to gather contrary views was important.

Given the potentially contentious nature of the topic and the setting, the survey provided the best opportunity in this study for a version of an authentic voice to be articulated. The value of this was apparent when at the end of the survey they were invited to make any additional comments they wished, one respondent who had a positive view of inclusion fed back that they didn't think a survey was the best way of inquiry, they should have had a discussion: **"could have been done better by looking at inclusion a little more generally or even better through discussion"** (PT07 class support staff). While in other parts of the survey ambivalence or hostility was expressed. For example, in response to question: *Have you any comments or reflections (positive as well as challenging) about "Inclusion as meeting the social/academic needs of pupils with disabilities" for [name of school] or you?* **"It is becoming increasingly more difficult as a teacher to have a positive view of inclusion as it takes more and more time and resource up for a small minority of children"** (PT 47 teaching staff). Based upon what happened when interviewing the Teaching Assistant group, it is doubtful that those latter voices would have been heard in an open session with the equal weight they were accorded in the survey. The value of the survey was also in the follow on, having engaged with it the feedback was that staff did start their own conversation.

Four features were given priority in the design of the survey, all drawn from good practice in the literature (cf Iarossi 2005). Firstly, it was anchored in a theoretical framework so that the reference points for the data and findings could be located for inquiry. In this case it used the work of Göransson and Nilholm (2014) whose four levels of description of inclusion provided the architectural structure of the survey. Secondly, as much as possible, the survey would operate in the manner of a structured conversation, with the script taking the voice of the researcher, but one that sought to avoid and limit bias.

Archer (2000) highlighted how internal conversations become objects when they are converted to a form which allows for the person to see them externally such as in a questionnaire/survey. Consequentially, from both sides of the survey this was partial conversation from both parties and required interpretation in the light of that. Thirdly, it would be accessible to all participants in language, voice and demands, recognising good research practice and principles in its construction.

Finally, it would be ethically robust to ensure the best chance of rigour and quality information. The design process worked through each of these features which were refined and tested through the question refinement, trials and associated feedback from the school leaders and outside experts of the early designs. The sub questions flowed from the Göransson and Nilholm (2014) framework (see below).

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Figure 15 Illustration of progressive models of inclusion from Göransson and Nilholm (2014, p. 268). Showing progressive and nested nature.

The specific questions for each level all started with how they understood the four descriptions in Figure 15. Then further questions were designed to probe each of the conceptual models and test their accounts using the background data including presence and nature of SEND in the school, profiles of progress, attainment, reports and observation of the

setting reviewed from the school. Some questions were open while others asked for a rating on a scale.

The survey's primary aim and design was to assist the school, but it was set up to comply with University and local school ethics procedures and processes so that if useful information did emerge it was possible to make use of it. The data was imported in as secondary data into this project.

How data was processed - tools

All forms of data were processed as transcripts, with recordings having been converted to text, checked for accuracy, and anonymised. Areas that were potential for risk to confidentiality breach were identified, so that in writing up those areas were not referenced. The original recordings were kept secure and separate in a locked safe and on a separate secure personal single access university server until the conclusion of the research. Following conclusion of the research and project completion, original data will be securely disposed of as per ethics approval.

Transcripts once anonymised were processed using both Computer Assisted Qualitative Data Systems (CAQDAS) and hand coding. The CAQDAS chosen was NVivo which was individually purchased (at the time of starting the study NVivo was not supported by the University). As a researcher with literacy difficulties, the use of computer systems offered relatively easier access to data management and retrieval. It was selected as it offered a flexible range of tools to track and link work on the data providing a secure system and audit trail for the study. NVivo was particularly well suited to examining the fine detail for 'bottom up' coding in the data (See appendix D).

Early data analysis made use of hand coding while technical skill acquisition of NVivo progressed. Later hand coding was used to hold in a single visual view a wide range of codes (some 222 for one phase), which could be easily physically manipulated allowing a top-down

wider scope of engagement. The hand coding results were then entered back on to NVivo to then progress the next detailed level of work. Both forms of data engagement were researcher led, in that processing of information was not devolved to a system and was retained by the researcher. However, the computer system allowed for faster searching and tabulation at the granular level and administrative efficiency at the higher level. Both systems allowed for the researcher to adopt a dual position of being within and part of the research and also to be an outside observer of it. Archer (2000) across her exploration of agency described how writing transforms thoughts into objects that are separate from the person and can be viewed as though from the outside even if viewed only by the person, creating a dialogue of internal and external worlds. This constituted the activity of engagement and analysis facilitated by the processing tools. At the final stages of analysis there was a move from NVivo to hand coding/analytic memos which was then re-entered back in summary to NVivo to contribute to the code book (appendix D).

Another form of processing was to create illustrations to synthesise complex structures and relationships derived from the data, some of these were mind maps drawn using specific software (Inspiration), others hand drawn and annotated (see appendices A and D for examples). The process was about identifying constructs and concepts that described the data, that also represented how participants' experiences and meaning were shaped and constrained, and how as a researcher I responded to the material. In the final stages, two graphics were constructed derived from the data, one for the structure of the education-inclusion system (the Arc of Education Figure 20 and Figure 21) and one to describe the outcomes of the interactions of structure and agency (Discontinuity and Disjuncture Pathways Figure 25). Those then shaped the final writing up which was the last stage of processing the data consistent with Braun and Clarke's (2006) strategy and approach for thematic analysis.

Participants

To preserve confidentiality and anonymity no details of the participants' identity, geographical location and individual circumstances in the thesis are provided, pseudonyms are used throughout. On occasions even the pseudonyms are substituted for participant numbers to secure the anonymity. The characteristics in terms of group are described instead. The details of the individuals who constitute the groups were accessible for review by the supervisory team. The two meta-case studies were constituted to provide representation of known features of influence such as locality socio economic status (SES), individual SES, types and size of school, levels of experience, levels of education, age of children at time of data collection and other relevant factors.

Parents Case study constitution and overall profile

Structure of parent case study

The parent case study comprised of

- Single interviews with 10 families
- 4 small groups of 2-4 participants

Table 2 Parent participant context details. Showing details of child's level of education at time of interview and type of data collection. For the purposes of anonymity, the parents who went on to form the longitudinal group are not identified in this table.

| Name of Parent in study | Name of their child(ren) in study | Level of education at time of interview |
|-------------------------|-----------------------------------|---|
| Ann | Andrew | Secondary |
| Beth | Bob | Secondary |
| Cathy | Colin & Clare | Secondary & Primary |
| Diane | Dave and Debbie | Secondary and Primary |
| Elliot & Elizabeth | Ethan and Emma | Secondary & Secondary |
| Gemma | George | Primary |
| Karen | Kevin | Secondary & Primary |
| Lucy | Larry | Secondary |
| Nora | Nathen | Secondary |
| Oliver | Owen and Oscar | Secondary and Secondary |
| Penny | Peter | Primary |
| Rachel | Robert | Primary |
| Susan | Sarah | Secondary |
| Tracy | Thomas | Secondary |
| Vera | Vince and Violet | Primary |
| Wendy | Wayne | Primary |
| Xavier | Xara, plus two brothers | Primary |
| Yvette | Yves and Yasmin | Secondary & Primary |

There were 19 parent participants in the parent case study, there was a distribution of pupil ages with at least one child in every academic year from Year 2 to 11 across the span of education, with a cluster at Year 7 & 8 (key stage 3) with 10 of the 26 children referenced in the study in Year 7 or 8 at the time of their interview. This was useful since parents were able to look back over recent primary education and transition and had a point from which to evaluate its efficacy and impact. 5 families formed phase 1 of data collection, and 4 of those went onto form a longitudinal group that were interviewed 4 years later. There were 17 interviews with some parents including the longitudinal group having been interviewed twice. 4 small group, three with parents and one joint parent and teacher group were also conducted. The size of the small groups was between 2-4 participants. Small group differed from single interviews in that conversation took part between participants as well as responding to researcher, rather than just interaction with the researcher in the interview.

Demographic data abstracted from interviews.

A purposeful decision was made not to seek individual demographic data in the opening of interview data collection to convey to the parent the focus was on their child's story and their experiences. This removed the explicit social markers as part of the opening dialogue. Given this was not seeking to be a representative sample or draw from that tradition that data would not have been of primary use to advance the inquiry. Nevertheless, across the interview's participants chose to share a range of information that allowed general demographic data to be inferred. To the best that could be deduced there was no participant where the family was entirely reliant on benefits or was engaged in unlawful employment/activity. These hard-to-reach groups are not represented in the study. There was a range of income status with some families accessing benefits, and/or having insecure employment, while others not. Highest educational level ranged from leaving school early with limited qualifications to technical and university professional. Occupational roles ranged from unskilled to professional. Occupational role was not necessarily linked to highest level of qualification. In a small number of households, the mother was not in gainful employment but providing family support. There was a small sub-set of parents or children who had long term health conditions independent of dyslexia-SpLD and a range of marital/ family status although there were no known single sex families. The communities the participants drew from represented a range from rural to urban to city. While the case study included participants, who created a balance within it, for features that were known to mediate outcomes, it is also true that the constitution of the case study had limitations. These are known weaknesses of qualitative enquiry arising due to size and efficacy of processing data. This does not mean that findings may not be relevant and meaningful to other groups not represented in the case study. Rather, contributions and insights from these groups to shape perceptions and understanding is missing; giving for the study a relevant but partial account, which would be open for further development.

School case study constitution and overall profile

The overall purpose of the school case study was to offer a counterpoint and critical perspective on parental accounts from a school insider stance so that parental accounts could be placed in context of the wider education system. The purpose was to understand the ways schools as entities and school staff specifically understood dyslexia-SpLD and inclusion at practical level in a functionally typical mainstream primary school.

The school case study comprised of three components.

- Single Interviews with 7 teachers
- 2 small groups; 1 joint with a parent (4 participants), and 1 of learning support assistants (LSA) (10 attendees 5 active participants)
- A single site survey of 36 participants

School staff interview profile

For the interviews, 4 setting in 4 differing Local Authority areas were engaged, and in three of them participants reflected a range of length of experience. This was split into early 1-3 years, experienced 4-15 years and senior 15+. The classification did not reflect designated authority role in the school. The three SENCOs had also a range of differing lengths of experience and training.

Table 3 School staff interview demographics

by level of experience, type of locality for school location, size of school and data collection method

| Name | Level of work experience | Type of locality of school | Types of school | Type of data collection |
|--|--------------------------|----------------------------|--------------------|-------------------------|
| Frank | Senior Experienced | Urban challenged SES | Large primary | Interview |
| Fraser | Experienced | Urban challenged SES | Large primary | Interview |
| Fay | Early | Urban challenged SES | Large primary | Interview |
| Hannah | SENCO | Suburban | Mid-size secondary | Interview |
| Hara | Experienced | Suburban | Mid-size secondary | Interview |
| Holly | Experienced | Suburban | Mid-size secondary | Interview |
| Jane, Jill, Josie, Jackie, Joan, Jennifer, Julia, Jasmin, Joy, Jenna | Experienced TA | Suburban | Mid-size secondary | Small Group1 |
| Gwen | SENCO | Rural | Smaller primary | Small Group2 |
| Gabby | Experienced | Rural | Smaller primary | Small Group2 |
| Gracie | Early | Rural | Smaller primary | Small Group2 |
| Imogen | SENCO | Urban: challenged SES | Mid-size Primary | Interview |

School and staff profile for survey

The relevant demographics of the survey data were: 18 support staff and 14 qualified teaching staff. No further demographics were collected as outlined in the ethics sections (see page 137 and appendix B).

The school survey was for a mid-sized primary that had end of key stage 2 results that met the national average. It was a survey which was well supported by staff. There was about equal teaching and support staff responses. Overall response rate was very good (details of percentage withheld for anonymity), giving high confidence that the population was well represented. The school was in an urban area and while it had average rate free school meals it had a wide divergence of parental SES in its profile. It had slightly above average local and national rates for Statements of SEN and EHCP, but notably more than many of the local schools at the time of the survey. The context of the school was that it was located generally within the midpoint of average for the national profile.

Application of Method to Case studies

Previously the timeline of the research project had been briefly outlined. The information above was applied to the construction and application of research tools and the development of the 6 sub-groups that comprise the two case studies of the overall study. The summary table proves highlights. However, as noted previously and illustrated diagrammatically below there was an iterative process in the construction of the groups and the material explored with each of them.

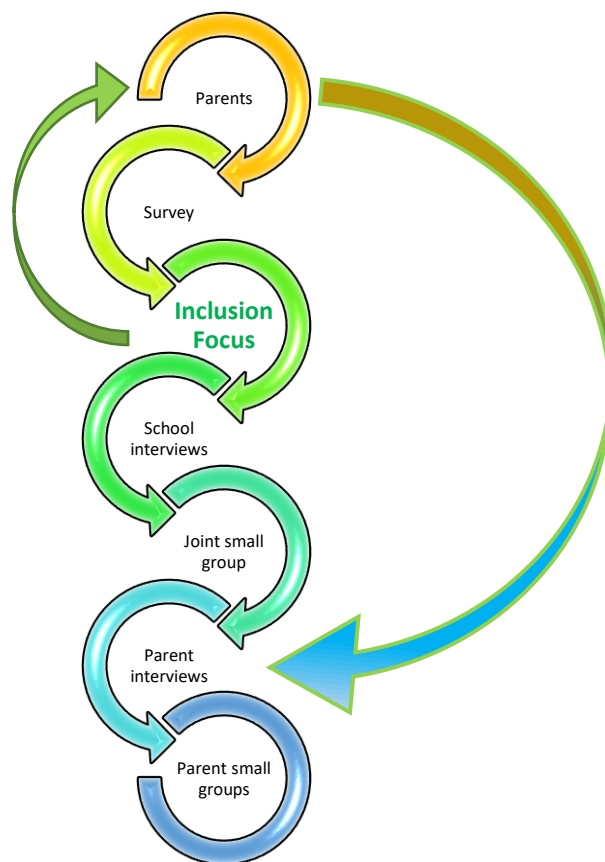


Figure 16 Diagrammatic representation of data collection stream, showing the points where data was re-examined in light of new data, or fed into later stages such as the formation of the longitudinal group.

In Figure 16 the two yellow loops at the top form phase one at the end of which a focus on inclusion was identified as a topic of inquiry. The data was then re-examined in light of that (green arrow showing feedback into original data) and in phase two which is the green to blue loops, further data cycles were initiated. 4 of the initial 6 parents in phase one were re-

interviewed to form the longitudinal group represented by the arrow with colour transition in the cycle. An unusual feature is the parent longitudinal study that captures reflections at two points in time, 3 plus years apart for four parents who had secured additional support for their child. This augments the more typical snapshot approach to capturing parental and teacher accounts and provides an account over the Arc of Education which can act as a reference to the other parental and teacher interviews. The above section describes the structure of the methodology and the methods applied. The next section deals with the agency by the researcher in engaging with the data.

Analytic strategy and practice

As described previously the orientation was to critical realism, the method was case study and the analytical tool for examining the data was thematic analysis as described by Braun and Clarke (2006) utilised through the lens of a critical realism orientation. The next section will examine the use of thematic analysis and its framing with critical realism.

Use of the Braun and Clarke (2006) framework

Thematic analysis as described by Braun and Clarke (2006) is a 6-stage pathway for engaging in a form of data analysis that seeks to identify the patterns of consistency (and by implication differences). It is a strategy that could be applied to a range of research orientations drawing upon narrative data. However its progressive pathways to examine underlying themes is consistent with the process of identifying demi-regularities, with the abstraction and retroduction of critical realism as described by Fletcher (2016). The following section describes the researcher process using both Fletcher (2016) and Braun and Clarke (2006).

Thematic Analysis starts with familiarisation and concludes with writing up, which is not additional too, but a fundamental part of the analysis. It is a form of reductive qualitative data analysis that through progressive iterations of data engagement seeks to encounter,

become familiar, and then reduce the accounts to a central descriptive or explanatory essence of the data. In this research project that process was tracked through using NVivo and hand coding (see code book in appendix D).

Descriptions generated through this process may also have capacity to speak to wider social accounts and the field. As a strategy it has the advantage of being neutral to the researchers' personal philosophical position and allowing their stance to shape their interpretation of the data in representing the voices and accounts of participants. For the project those were captured in the annotations of the text, research memos written and the extended writing. A key part of such a strategy is to ensure the reader of the research can understand the ontological and epistemological lens of the researcher through which the data has been processed. In this study that has been laid out in the literature review, the first section of the methodology chapter and is reinforced in the write up of results.

The two key tasks in this type of analysis are eliciting the observable realities as perceived and understood by participants and captured in their accounts. The process started with an in-depth familiarisation through listening to the audio multiple times and line by line engagement and reflection. The observable realities are open to independent verification and samples by way of extracts inform all the results chapters. Those extracts are central to chapter 5 *Visibility of Dyslexic Children and their Parents within the Arc of Education* (Visibility) and also form an anchor point in the analysis. The second aspect is identification of the unobservable realities, these are interpretive by nature, shape researcher perspectives, draw upon the researcher's personal positions, in this case Critical Realism and its constructs of retrodution and abstraction. An example is in appendix D where annotations were used to capture researcher response to content. These allow inference on forms of potential of causality. For this project they were represented in the writing up process through the impact

of discontinuity and disjuncture, types of parental agency and the role of the Arc of Education for the collective influence on the enactment of inclusion.

The assumption of the participants' accounts is that they were authentic and that they were responding to an authentic researcher. However it was assumed that the participant was positioned by their own interpretation and presentation of public self (cf. Goffman, 1969). To that end a range of ways of capturing information collectively were used so that there were different slants and openings on the way information was positioned and disclosed. This was using in-depth interviews, small groups, and survey the tools of which were discussed at the head of the chapter. The value of case study was it allowed for a multiplicity of participant positions to be accommodated.

Identification of recurrent themes formed the essence of the Braun and Clarke (2006) analytic strategy and is consistent with the demi-regularities that are part of the epistemology of Critical Realism (Fletcher, 2016). In this study those observable realities were verified by cross reference within the case study data. This was ethically and ontologically appropriate, by allowing the participants to be through their voice the validators or challengers to other participants' accounts. The role of the researcher was to ensure that the different competing voices were represented. This approach drew from Yin (2018) work on taking a critical stance and considering competing explanations.

That internal checking was a mechanism to reduce the risk of post hoc fallacy (post hoc ergo propter hoc) and acted as check for rigour. In this respect the diversity of the constituent parts of the case study secured its robustness, by allowing challenges to the identified demi-regularities when they did and did not occur. The demi-regularities that constituted the themes could be independently verified. The process was captured by the audit trails generated by NVivo (see appendix D) or supplemented by Excel charts or visual records when using hand coding.

Indeed, that external review was part of the role the supervisors, who were all ethically cleared to engage with the data as needed, to challenge or provide technical guidance, as well as were expert in different aspects of the study field. However, one of the way's rigour was secured was as the study progressed and emergent findings were identified, these were presented at conferences and engagement of a wider set of commentators and observers allowed for validation and development (see appendix A). Finally, the unobservable realities also apply to the researcher whose own awareness and interaction with the data shaped actions and subsequent engagement. That aspect is captured in the reflective account (page 329) at the end of the study and in the code book (appendix D).

Process

Overview of process

As critical realism does not have a well described and documented methodological history in the ways other qualitative approaches have had, the enquiry adopted the methods and stances that were relevant for the stage of analysis. This drew upon debates and critiques about the nature of knowledge, rigour, and case study in Denzin and Lincoln (2018). The early stages of open coding were data driven, without pre-ordained ideas. However, as a researcher I brought the academic, social and emotional knowledge of prior study and personal circumstances. Later stages had drawn upon the emergent data framework and extended it for depth and complexity while narrowing focus.

There were two aspects to the process: the doing of data analysis and the recording of the doing for continuity and audit. The process was one of narrowing the focus from broad to specific. There were three broad chronological stages to this that ran alongside the Braun and Clarke (2006) strategy. In essence thematic analysis (Braun & Clarke, 2006) presents as a progressive iteration of the data, in contrast this work had multiple regressions back to the

data (see Figure 17 below as a mini example) reverting to lower levels of the thematic analysis across stage one and two outlined below to achieve effective abstraction and retroduction.

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Figure 17 Extract from NVivo nodes showing re-visitation of nodes

For ease the stages have been briefly described and their links to Braun and Clarke (2006).

Step one: Braun and Clarke (2006, p. 87) phases 1 & 2 was open coding exploring parental data with no preconceived conceptual framework. Stage 1 was the examination of understandings of inclusion by school staff from within the framework outlined by Göransson and Nilholm (2014). The task was to identify demi-regularities that formed early coding nodes. This work had also drawn on the knowledge and information for the phase 1 parental interviews. Both data sources were then considered alongside each other.

Step two which links with Braun and Clarke (2006, p. 87) phases 3, 4 & 5 considered the assumptions of inclusion using Göransson and Nilholm (2014) as a guide to this stage. The engagement with debates around dyslexia-SpLD and methodological inquiry were the background to informing this stage. The parental interviews were compared with the perspectives of school staff. The task here was focused upon abstraction. This work cumulated with the early findings around expectations with regard to inclusion by parents and school staff and setting the stage for phase two inquiry that then specifically explored that issue. See appendix D for an illustration of this work.

Step three which links with Braun and Clarke (2006, p. 87) phase 5&6; was the specific examination of experiences, perceptions and understandings of how dyslexia-SpLD and inclusion was comprehended by participants, as well as how inclusion was enacted for them.

The key task here was retrodution of testing plausible rivals and accounts to provide explanatory frameworks. This then formed the narrowed focus of the thesis in its write up (see appendix D).

Audit trail

Audit is a means to track decision making and enable transparency, and forms one of the checks for rigour. To that end as discussed above CAQDAS was identified as an appropriate tool, to manage what was likely to be a significant data set. CAQDAS does not do the analysis, which remains the province of the researcher; but can enable efficiency of tracking analysis and some forms of visualisation. The central features of NVivo used in this project were the management of codes and creating an audit trail of conceptual development over time. The process is illustrated in appendices A and D with extracts from the project code book tracking the data processing (see appendix D).

The key to qualitative data analysis is the identification of unit of meaning that could be an utterance such as a pause or a longer description of an event. Both occurred in the data. The researcher's task was to identify what was shared across accounts and what was particular to a participant's or group of participants' accounts. Then to understand what may have driven those stories and description. This was not only at an empirical level but also to identify through abstraction and retrodution process those aspects below observable realities. One of the non-observable reality features was inclusion itself, the subject of the study, which could only be inferred from actions, accounts of events and situations.

All raw data once collected, was loaded up onto a password protected computer system and stored safely. The process of anonymisation and correcting typos added by accident in transcription also ensured that text reflected what was said and the manner of its saying was also part of the familiarisation strategy. The following section provides a description of process which is detailed out in the code book (appendix D).

Phases of analysis

Phase 1 *Familiarisation*

For interviews

The first stage was repeated listening to each interview and re-listening to specific sections of interest for the nonverbal features of the account to place the words spoken in context. Although linguistic analysis was not a focus, there was a need to be familiar with the participants meaning.

For Survey

Material was downloaded from Survey Monkey to Excel which was imported into NVivo and printed out, familiarisation took place through reading through the collected responses by individual, group and question.

Phase 2 Open coding

The deconstruction of data from its original chronology into an initial set of non-hierarchical nodes. This was participant data led broad open coding.

Phase 3 Searching for themes

Open coding allowed for the array of features around inclusion for a child with dyslexia-SpLD in education to be captured from the data. The 163 codes were constructed under 42 categories each was reviewed individually to check the description/definition matched the content of material coded to the node and if needed modification to the description were made so that material and description/definition were aligned.

Phase 4 Drilling down

This involved breaking down the recognised categories into subcategories to better understand the meanings embedded into the account. The original 42 categories were reduced to 29 but supported by 256 codes. This process allowed for exploration of the demiregularities and expansion as the phase 2 data was coded into the phase and so used some

initial top-down framing to sort codes, but also new material involved bottom up inductive coding consistent with the approach described by Fletcher (2016).

Phase 5 Consolidation: defining and naming themes

This was the stage of conceptually mapping and collapsing categories into a broader thematic framework. It involved substantial work in coding and consolidating material. The units of meaning coded per theme ranged from 1,808 to 10,544 (see appendix D). Use of analytical memos was prevalent as a mechanism to move ideas from inside my person, to object outside as described by (Archer, 2010).

Analytic memos were used extensively to systematically review the framework developed in phase 5 and to ask questions of the data. Those memos were also the source of supervision discussion so that process had some form of external scrutiny and challenge. Those sessions were recorded and further analysed and used to clarify and validate the thematic development. When necessary, the earlier phases of codes and data were revisited and reviewed. There were several iterations of this cycle securing progressive depth, understanding and refinement on successive topics. The memos were used to reduce the data for a series of nodes to a series of documents which also explained the analysis. An iterative and systematic process of editing and consultation took place with memos to reduce overlapping content and improve clarity; so that a cohesive chapter was created at the end of the process.

There were two ways analytic memos were used. The first was throughout the data coding, where periodically, extended writing was generated. Some of these were short responsive memos, some longer. Secondly throughout the project the data analysis moved between NVivo coding and drafting memos to substantive writing of extended analytic memos on each of the higher order codes. These analytic memos examined the theme of inclusion from a particular theme perspective. The focus of the work pivoted through a range of lenses,

methodology, spatial constructs of inclusion, relationships between parents and schools, the nature of groups, inclusion and exclusion, the legal framing of education, and finally agency.

Each of the analytic memos identified:

- a) The focus and content of the higher order theme
- b) The patterns within the data and codes, for cases that supported theme and those that were exceptional. The latter cases were important for depth and quality of analysis.
- c) Creating a narrative driven by the codes and context that addressed the research question. The narrative considered what was common, exceptional, clusters and explored this from both the observed and unobserved realities using the three levels of critical realism framework of real, actual and empirical.

Phase 6 Abstraction and retroduction into producing the report

Synthesis into final thesis and account

The final stage of synthesising was multifaceted. It involved sketching models and conceptual maps to illustrate the relationships between relevant codes and themes (see appendix D), the writing up of a theme and the integration of the two models and five themes to tell the story of inclusion for children with dyslexia-SpLD privileged from the parent's perspective.

Those themes emerged from the analysis described above and are represented in the results chapters. The themes reflect the critical realism orientation toward ontology and epistemology, of empirical, actual and real levels. These shaped the level of analysis. A primary theme of Visibility was then explored in greater depth by considering how three other themes, Discontinuity & Disjuncture, Agency, and Structure constructed or contributed the theme of Visibility. In turn the collected literature and results shaped the final theme the Illusion of Inclusion. Although the structure theme represented by the Arc of Education was a result of

later stages of data analysis, in the presentation of the thesis it was placed at the beginning of the results to help orientate the reader.

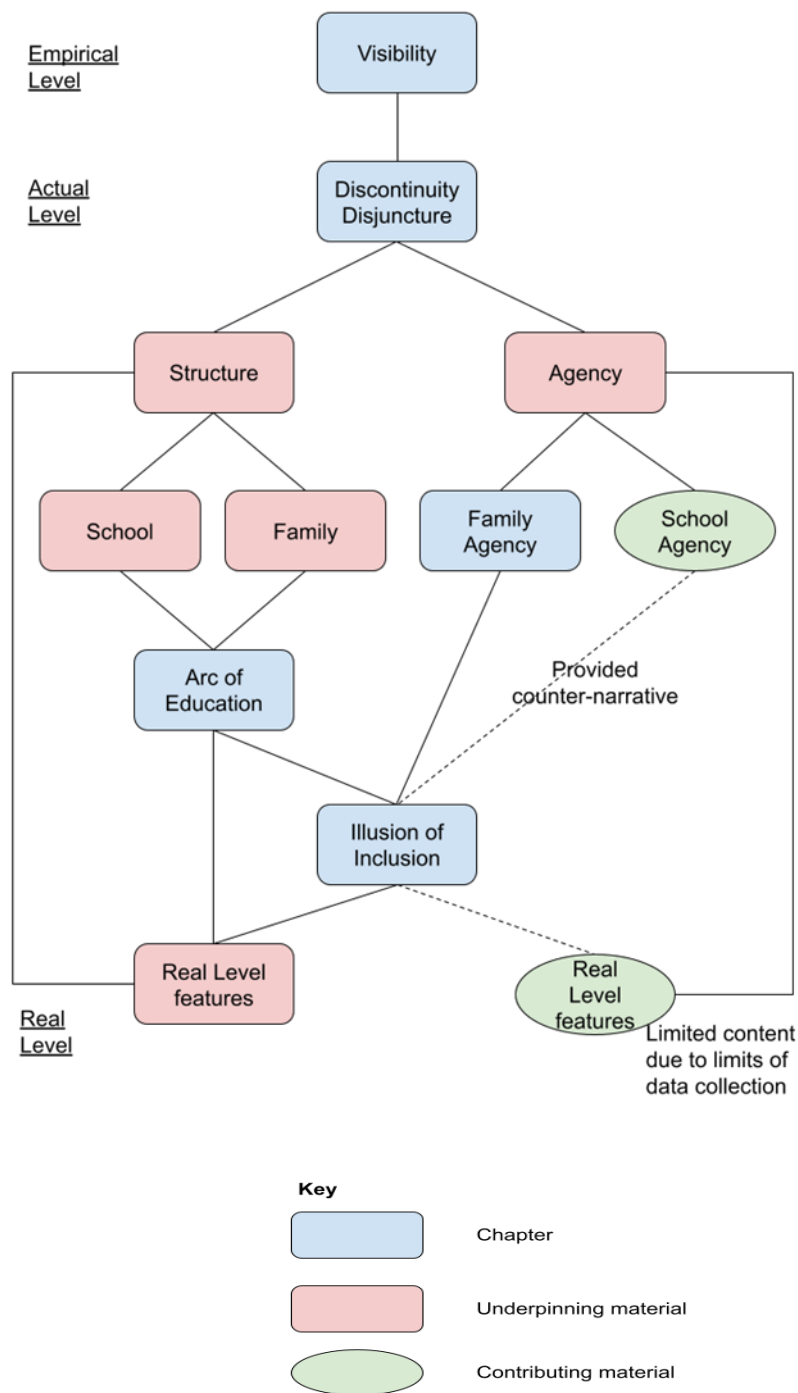


Figure 18 Data Processing of Themes and Links to Chapters in Thesis, also showing the three levels of critical realism structure of Empirical, Actual and Real

In the figure above, the pathway of how findings were derived and what material is represented in the thesis through the results chapters is illustrated. The limitation of data collection and space for representing material in the thesis meant that for two areas: the examination of agency for the school case study, and the abstraction and retroduction at real level of features of agency, were limited to contributory into the main results chapters. The orientation of the research meant decisions had to be taken about selection for what material was necessary to be included to provide an effective and rigorous answer to the question which the data supported. This also meant decisions had to be taken about what not to include and this was guided by using the sub research questions (that head each chapter) and maintaining focus on the research question.

Ethics

Ethical consideration was a central organizing framework for the whole study. The parent participants were vulnerable individuals by virtue of the children's needs and the system they needed to navigate. Further, their children were young or vulnerable and not able to consent for their parent's participation. Consequently, all research decisions were made from the initial construction of the study with awareness of the risks, with a focus on preserving anonymity and additionally confidentiality in any public facing documents or discussion of findings, and anonymity generally. The challenge of meeting that was in part addressed using case study which moved the analysis and write up from the individual to group. Both confidentiality and anonymity were important for participants to have confidence to share information with the researcher, particularly around sensitive topics.

Prior experience as a health professional did help me in being able to navigate this challenging terrain effectively. This was so when judgment had to be made about if a line of inquiry needed to be dropped, or participants were likely to disclose information that was not

in their interests to do so. Both types of incident were rare, but they formed part of the ethical dimensions of the study.

A final ethical dimension was to ensure the contributions of participants were not distorted and to only engage in the data when I was able to do so effectively. There were points in the lifecycle of my own children's education which meant that a fair engagement with the data was neither wise nor possible and, in those periods, other associated work as undertaken for example being co-author on SEN support a Rapid Review of Evidence for the Department of Education (Carroll et al., 2017).

Chapter 4: Setting the Context: The Arc of Education

Introduction

This opening chapter of analysis provides a structural description of the education milieu encountered by children and parents when they enter typical mainstream provision (TMP). That is provision ordinarily available in the local community open to all, and generally held to account by Ofsted, following a pathway to national assessment and tests. The structure was derived from the data towards the end of the process, but is presented at the beginning of the results to enable readers of the work to have a visual representation to access as they engage with the subsequent results chapters. The derived structure is referenced as the Arc of Education. To understand how parents perceived, understood and enacted inclusion, it was necessary to describe the structure they were engaging with.

The sub-research questions related to this chapter:

- What form do the structures involved in education take?
- Does the form, as perceived and understood by parents and school staff, illuminate a potential causal explanation for the nature of inclusion for children with dyslexia-SpLD?

The gaps in the literature

Problems in describing the structure

The Arc of Education is a description of how formal education is constructed through interacting systems and structures. With rare exceptions, the focus for the literature addressing inclusion is what happens within the Arc, rather than the structure that shapes the Arc. Limited attention has been given to how what goes on within it, has been shaped by the context. One of those exceptions was Lindsay (2003), who challenged the idea that a focus just

on the within-child features or their immediate interactive responses to features of the environment was sufficient to address the inclusion knowledge and practice gap. He proposed that alongside consideration of within-child factors, research “pertaining to all aspects of inclusion including classroom practice, school organisation, LEA systems and government policies” (Lindsay, 2003, p. 9) required rigorous examination. This was one of the limited accounts of the field that recognised multi-level complexity. More recently, Done and Andrews (2020) have articulated a critical evaluation of the internal contradiction of a universal education system focused on inclusion adopting internal segregation as its mode of operation and the implications of such “selective segregation” (Done & Andrews, 2020, p. 447).

However, while both have extended the critique of the common accounts of inclusion and both have acknowledged structure as being more than the child in the classroom/school, it remains poorly described. None of the work reviewed has addressed the way in which the architecture of learning and education, both at a physical and cultural level explain the outcomes for an individual child.

Assumptions about orientation of structure and inclusion with respect to dyslexia-SpLD

The implicit assumption of the literature is that inclusion is a group level phenomenon, which is understandable as the term inclusion does presuppose the presence of more than one person. This presumption has led to the privileging of multi-person accounts of inclusion and a focus on the doing of inclusion. This includes debates around the practical challenges of group diversity in a process-driven system, some of these were articulated in the literature review. Inherently, the drive of humans towards progressive development creates a push upwards. The resolution of the gap in differential attainment has been to provide support to level up, as Levin (2010) described in the examination of how large regional/national programmes to reduce literacy attainment gaps were implemented and fared.

When it comes to children with dyslexia-SpLD, this has not proved to be a wholly effective strategy. As discussed in the literature review, there is a persistent failure by a sub-group of pupils to respond to intervention, even very highly specialised and expertly delivered forms of it. For example, as previously discussed, in the study by van Rijthoven et al. (2021), who combined a spelling and phonics programme for the lowest performing 10%, less than 50% of participants were able to move out of the bottom 10%. While intervention was of use, and any success is to be celebrated, it was not a universal solution. Those children and young people that respond may still have limitations that are hidden constraints, as Muter and Snowling (2009) found in their longitudinal study. Across the national data, while some improvements to the outcomes for children with dyslexia-SpLD from education have occurred, the rates of relative success have remained persistently poor at around 30-35% securing the benchmark of GCSE maths and English (Gov.UK, 2020a, 2020b). In the figure below the data for 2020, detailing the last year of examinations (2019) prior to the pandemic illustrates the discrepancies.

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***Figure 19** Outcomes of 2019 national examinations showing comparison between non-SEN and SpLD pupils*

This is despite a concerted campaign over many years to improve the outcomes, which while from a very low position have shown improvement, the absolute level and the relative gap have remained steady over recent years. Inequality in future prospects and opportunities is therefore a recognisable part of the outcome of education and adds to or part of the regional differences in educational outcomes (Johnson, 2020).

Addressing inequality, the role of structure and agency

Two problems in reducing long-term, educationally-mediated inequality were identified by Ellis and Rowe (2020). The first was the acquisition of literacy skills and the second was the relative gap between pupils. Both impact upon the development of agency, autonomy, and levels of dependency in an educational context, as Vaughn et al. (2020, p. 728) noted *“the need to develop contexts where teachers recognize and build upon their students’ ideas, languages, interests, instructional needs, and strengths. Agency is at the core of such learning spaces”*. In the Ellis and Rowe (2020) study, the whole curriculum, pedagogy and support system were reconfigured. The outcome was that all pupils’ literacy improved, irrespective of poverty indicators but the gap between pupil groups was only very marginally reduced. This finding of failing to catch up was also consistent with another study by Fuchs et al. (2015) that found the raising of standards and expectations generally meant that the relative gap did not close, even if skills did improve. In the Fuchs et al. (2015) study the comparison was made between inclusive whole class teaching and specialist teaching, finding that the inclusive teaching fared worse, but neither remediated the deficit. Both studies dealt with educational structure from a policy-practice orientation of raised attainment. From the literature then there are limitations on the effectiveness of individual and whole school interventions in closing the gap, but to varying degrees, depending upon the types of support enacted, individual improvement could occur. The primary focus of both studies was the delivery of learning, rather than the architecture of universal education and inclusion.

The Arc of Education

Repositioning the orientation of the structure

In this study, the structure that constitutes the Arc of Education has been re-imagined not from a group level but from the child’s perspective. It was developed to consider how the child is positioned in and by the structure and what such perspectives reveal about how the system is experienced and navigated by the child, parents and teachers. By taking a novel

perspective this opened up new ways of examining what has been a persistent account of educational inequality and personal distress (Kirby, 2018; Kirby, 2019, 2020a, 2020b).

The analysis of data identified several recurring themes that allowed for a description and representation of the structure. These were then graphically rendered as illustrated below.

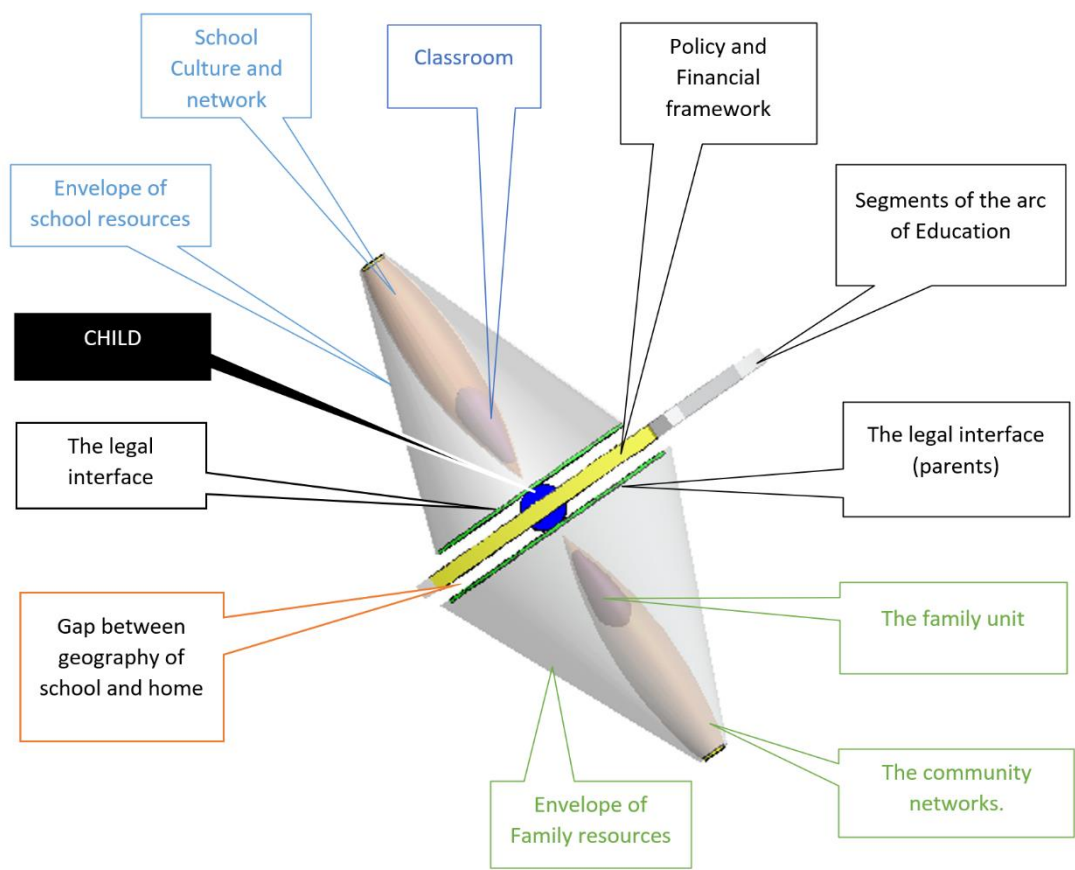


Figure 20 The relationship between the key features of the Arc of Education viewed from a side on perspective. Each of the components situated the child as located across two systems.

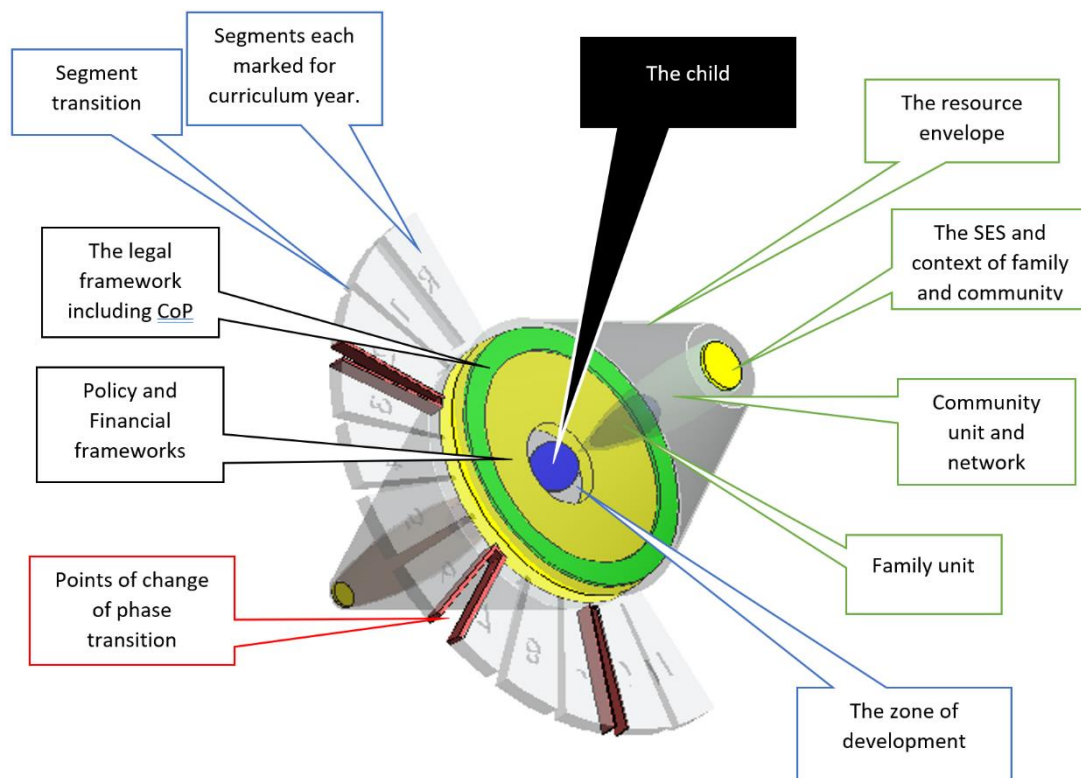


Figure 21 The relationship between key features of the Arc of Education viewed from the parent perspective. Each of the academic years in the Arc of Education is a segment that acts on the child successively.

The geographical boundaries

Schools had boundaries that are physical, temporal, and cultural, the latter with its own substructure with governors, head teacher, senior leaders, teachers, and support staff in a hierarchical arrangement. The borders were physical (school gates) and administrative (rules and contact systems) but also had variable permeability. The type of boundary also represented a wider expression of how the school valued the parent and their presence, as Dave's mother Diane's account illustrated:

Well, when he went to [primary school 2] it was absolutely fantastic. The teachers were there at the door at the end of school, at the beginning of school. I could speak to them whenever I wanted to

But the permeability of a boundary also extended to the act of remote communication as Yves mother Yvette described.

just knowing that they're willing to have a dialogue is massive [...], with primary school they wouldn't even give an email address for us to contact them or anything like that.

Both parents are describing how the geographical boundaries around a school could be used to facilitate or obstruct engagement. Lake and Billingsley (2000) identified how communication was a factor that could lead to escalation or de-escalation of parental conflict as it impacted on parental perceptions. Barriers around sharing understanding and insights became a leitmotif through the parental data, but also did occur in the school interview data.

In the following extract Frank, an experienced teacher working in a socioeconomically deprived area, reflects upon children's capacity to be the conduit of information and parents' responsiveness:

FRANK: It's general things as well, like making sure that letters go home and not just put in the tray and forgotten to all the way to making sure they know which day PE is on and making sure they have their PE kit and trips of course, often parents haven't heard of the trip that's coming up even though three letters have gone back and a text message

The lack of visibility of both sides of the boundary was a relevant feature. Frank's comment on the child helpfully illustrated and located the barrier not at the parent level, but at the child one. This is a novel conceptualisation of how the barriers between home and school emerge, but also was an early demonstration of how the parent or teacher acted or could act as the child's voice and interest. That aspect had relevance across the data and is reflected in the results chapters.

The child

The first element was the child, they were central to the structure. Each child formation of the arc would have common elements as below, but their rendering of the

structure would be individual. This part of the structure was drawn from the many stories of children and their parents, and those are articulated across the further results chapters. A small scale qualitative study by Wolfe (2014) with 8 parents examined how engagement was affected by recognition of the parental contribution and knowledge (their voice). It identified how parental needs for communication and recognition of experience and understanding were important to empowerment, which in turn was seen as important for building children's resilience. The study also identified that the child operated between two settings. Willemse et al. (2018) and Thompson et al. (2018) identify how teachers are poorly equipped to manage family-school partnerships. However, in the middle of this is the child. An individual with literacy difficulties is every day returning to a setting that is taxing and has the potential daily to leave them in a raw state.

The data in the results chapters captures that these are children who do wish to learn, despite the difficulties. Rachel commented about her son **"He wants to learn, and that's frustrating, he wants to learn but he's in the lower groups"**. The challenges they face are considerable and the separation of the geographies between home and school and the lack of visibility of each to the other was important as a place of being away from sources of pain as Karen observed **"He's shattered. You can see it. He's constantly pale, he is shattered, really tired by the time he gets home from school"**. This model is the first that has schematised education and its structures anchored from the child perspective and in doing so allowed illumination of a complex structure in a novel way.

The culture

Either directly or obliquely researchers such as Belli (2021); Lithari (2019); Riddick (2010) have indicated how school and class cultures nestle within each other, but also created islands of practice. Belli examined through survey and interview how schools across an administrative region implemented inclusion and found very idiosyncratic ways in which children with SEND were supported. Lithari (2019) and Riddick (2010) examined the matter

from the parents' and children's experiences. That variability was still evident in this study and forms part of the evidence in chapter 5 (Visibility) and chapter 6 (Discontinuity-Disjuncture). The inconsistency which is explored through the results chapters extended into the degree of acknowledgment or acceptance of the construct and lived experience of dyslexia-SpLD, which differed across classes, schools and local authorities and contributed to parents and children's uneven experiences within the same school or between schools and in some cases Local Authorities.

The school culture

One of the findings in the study was how individual teachers shaped learning by what they did or did not do, and that this could have significance in the trajectories of a child's life, an aspect covered by Thomas (2013) in his review of the history of education. The culture of a school, which was shaped by the head teacher or someone in that leadership role (Morris et al., 2019), could be explicitly expressed as local policy (for example uniforms, homework etc.) or implicit ("**the school head, who isn't supportive of dyslexia, she said oh I can't do that**"). This culture was underpinned by policy and financial frameworks. Of these frameworks, the financial one was least transparent. However, it was also the one attributed by parents to be unchallengeable, as Lucy captured when no action was taken despite her son's needs:

**LUCY: I genuinely think it was all to do with money.
They've got too many kids that year that have been diagnosed with
dyslexia.**

Many of the parental moves between schools were guided by the perceptions of culture and those transfers out of phase of education focused upon the how schools responded to or viewed dyslexia-SpLD, for instance Yvette was describing what was different about Yves' new school "**they're dyslexia friendly anyway**". The resource envelope the school had available was also a consideration. When Lucy needed to change school, she examined the statistics and went on to comment about the rate of SEND for the school she chose "**if I can**

get Larry in there he's going to get more attention because there's not that many of them".

Lucy's account demonstrates that parents, from ordinary backgrounds, can develop sophisticated forms of evaluation, and that was demonstrated throughout the case study and is represented in the results chapters.

Mainstream education has hierarchies, some of which are embedded in legislation and regulation. For instance Governors (or Trustees of Academies) are responsible for the budget and ethos of the school but are not involved in the day-to-day work of the school (Governors for Schools, 2021). Other positions such as head teacher and SENCO are mandated in the SEND Code of Practice (Department for Education, 2015) but the relationships between them, teaching and support staff have variability but involve lines of accountability and influence (Gilbert, 2012). However, what the research found was that those lines of accountability lacked meaningful transparency to parents.

Visibility of school hierarchy to parents

Table 4 Results from content analysis of spontaneous references to roles or post holders in roles in parental interview for four groups of parental participants identified in the key. Highlights on key data have been added for ease of reading.

| | Longitudinal | Nora | Typical M/S provision (TMP) | TPM In- depth |
|--------------------------|--------------|------|-----------------------------------|---------------------|
| Governor | | | | |
| Head Teacher | 6.6 | 13 | 0.5 | 0.7 |
| Deputy/ Assistant Head | 0.4 | | | |
| Head of year | | | 0.1 | |
| Head of science | | | 0.1 | |
| Bursar | | | | |
| SENCO | 10 | 25 | 4.5 | 8.3 |
| Teacher(s) | 41.4 | 18 | 9.8 | 19.0 |
| TA/LSA | 4.6 | 9 | 1.3 | 2.7 |
| Staff | 1 | 2 | 0.3 | 0.3 |
| Administrator | | | | |
| School Nurse | 1.2 | | | |
| External Local Authority | 3.4 | 9 | 0.5 | |
| External NHS | 0.8 | | 0.2 | 0.7 |

Key

| | |
|--------------------|---|
| Longitudinal | Longitudinal Group - all these had Statement of SEN or EHCP |
| Nora | Nora - originally from TMP group |
| Typical mainstream | TMP excluding Nora |
| TMP in-depth | TMP in-depth interviews (Karen/Yvette/Lucy) |

The socio-culturally important area of school hierarchy was selected for more detailed analysis because observations from the data indicated a link between the parents' awareness of the school hierarchies, and the type of outcomes of securing support for their dyslexic child. A content analysis was done of the parental interviews in which the frequency with which different roles or people identified in the roles, was spontaneously mentioned. This was used as an indicator of the salience of the role/person in the parental narrative and the presence of the person as key to accessibility. Due to the varying size of the groups a mean was used to be able to compare groups, which did give the odd representation of a partial person (e.g., 0.5) in the count but was a fair representation of the strength of the report for that group. The results were then linked back to their perceptions of outcomes and effectiveness. Parents who had a

greater number of references and engagement across the span of the hierarchy appeared through their reports to have had more successful outcomes in having needs addressed with respect to their child. Further, for the parents who were less successful in securing support, the awareness of the school hierarchy appeared to be limited to a narrow band of the class teacher or equivalent and could involve the SENCO.

As will be discussed in chapter 7 (Agency), there was a link between the visibility and salience of the hierarchy to a parent and the type and nature of resulting inclusion. However, from a structure perspective it is useful to identify what a narrow band of real and recognisable visibility is open to parents of children with dyslexia-SpLD /literacy difficulties. Nora, mother of Nathan who had very severe dyslexia-SpLD, was an explicit contrast with the other two groups for the prominence of how the school structure was reflected in her account. She had on average the same level of contact with teachers (blue highlight), as the Typical Mainstream Provision (TMP) group but she did however have much greater contact with both Teaching Assistants and upper levels of school, SENCO and Head (orange highlights). As a family they were the only ones in the sample who finally secured specialist dyslexia-SpLD provision later on in secondary school. The importance of the roles occupied by staff in school and others and their contribution to outcomes is the material addressed across the other results chapters.

The segmentation span of the arc

The segmentation across the span of education, while recognised generally, has not been a significant focus of inquiry and arguably its impact on children with dyslexia-SpLD has been underestimated as a result. The principal focus of the limited direct literature for children with dyslexia-SpLD on transitions (two doctoral studies) has been around transfer between primary and secondary school. Lithari (2019) in her study of fractured academic identity did capture aspects of transitions and uneven educational experience but it was not the principle focus of the work. However, the data in this study highlights how both the formal change of

phase transitions are important and recognised by staff and parents, or at least some, but also less acknowledged in either the literature or participants' data was the impact of the internal transitions between academic years.

Transition from one academic year to another through both primary and secondary school had, from the data, particular impact on children with dyslexia-SpLD. The observation from the data and inference from the accounts was that unlike their typically developing peers, the children had not made sufficient progress in securing their skills at the lower level, so that when they started the follow-on year, they were in a relative deficit situation making catch up very difficult. Further, that there was a lack of transition planning to manage this. For the school survey (part of phase one data collection) access to the background school data on progress was provided as part of preparation of the survey development. This showed that up to Year 4 the children with SEN tracked below the non-SEN children, but at Year 4 a wide divergence happened, and the gap was progressively widening with each successive cohort year. This was data related to collective SEN rather than just literacy difficulties, but serves to illustrate, what the participants drawing from a range of settings reported; namely that once their children got behind it was difficult, if not impossible, to catch up and maintain parity, unless a significant change happened. Further, there could be marked and rapid disjuncture.

Rachel's account was an example of this phenomenon. In a group discussion about underachievement, she identified that for key areas of literacy there was a persistent failure to make sufficient progress "**Yes, yeah. Working towards** [Age related expectations]". The implication was that he had not achieved the required skill level, but there was no detail for her to inform the degree of deficit or plan to improve. Many of the challenges the children faced arose because they had made insufficient progress to be independent and exert agency to the next required level by the point of transition. This highlighted that access to education was composed of two strands. Firstly, the content, conceptual material which the parents

report was generally their child did not find problematic, for instance Karen on Kevin **“he likes science and he felt he was good at it”**. Secondly the skills of independent agency through literacy and numeracy which were repeatedly very problematic. These elements did interface, with the latter obstructing the former. Sometimes that was explicit and combined with transitions between years or phases of education and associated normed expectations, for instance Karen reflecting upon Kevin’s experiences on entering Year 7 **“He couldn’t write it down. He couldn’t copy off the board or if he did he couldn’t read it back to himself”**.

From this perspective education was segmented, each year being its own bubble. Projected needs were not an important focus for the school in the staff accounts except for one reflection by Frank:

We have a lot of children that we’ve said, you’ve got through, we’ve kept you going and then they are expelled or excluded within about two or three weeks [following transfer to senior school].

Generally, neither the near future of the successive year, or longer-term future which may lay outside their institution was a cause for examination of progress or outcomes in the school case study data. However, while parents were focused on the immediate, they also had a perspective on the longer term. They were uniquely positioned to do so. Parents were able to take a view across the span of the Arc of Education, in a way that was not open to many of the teaching staff who sat inside the system. For primary school, typically teachers only engaged with a child and family for one year. The segmentation was an important part of the discontinuity and disjuncture framing of education and it took effort to manage as Gemma, mother of George, explained:

When he started school, I gave the teachers then the heads-up. Then he went to the next teacher, and it’s followed-on from each teacher!

However, as Lucy found out, even with effort to manage transitions schools could reject salient information and not act on it.

It was basically I gave them a manual from the other people, the other school, of how to help him with his learning [...] If you typed his name into his student profile it just came up with a little picture of him, it didn't have anything, nothing.

The segmentation of education is a feature that has been hiding in plain sight for those studying dyslexia-SpLD. In general, the relevant research happens within a segment, or the segment is not relevant as the focus is on individual progress. It is only the rare studies such as the Snowling et al. (2007) 10-year longitudinal study that track development over time, but even those studies do not examine the ways the internal structure and segmentation of academic years impacted progress, and how those shaped aspirations and expected outcomes. What is discussed in chapter 6 (Discontinuity-Disjuncture) is how that segmentation generated uneven access to education and disruption of outcomes.

Legal

The legal framework was another area that was largely unknown to participants. Education is a legal construct; it came into being due to the legal framework and has been shaped through successive legislation. Providing parents and children comply with attendance requirements it remains largely invisible. Kirby (2018) identified through oral and documentary evidence the background and legislative history, while Lindsay et al. (2020) outlines how the seminal work of Warnock shaped the legislative landscape. However only one paper addressing the legal/policy issues was identified: Konur (2006). He noted the many barriers and high thresholds in getting needs met or redress for local authorities' failures in identification and meeting needs of pupils with dyslexia-SpLD.

Since then the law has changed to the Children and Families Act 2014 and the linked Code of Practice 0-25 (Department for Education, 2015). At the heart of the code is the presumption to inclusion, which is manifested by expectation of mainstream education, but as the study will demonstrate the presumption is poorly described and defined by participants,

some of whom did not even know of its presence in the code of practice. A second aspect was the mechanism of continuous review with a cycle of Assess, Plan, Do, Review known as the graduated response (Department for Education, 2015, s 6.44 -6.56). One of confusions was that the former graduated response was through progressive tiers of intervention which took place over time. It was a structure of additional provision that could be measured. This form of graduated response is more explicitly about the use of dynamic assessment and assessment data. Parents did not identify this cycle or the associated processes, which meant an important structural tool was either not being utilised in a conscious way or that it was not used to develop dialogue with parents and parents did not know how to engage it as a tool. Indeed, in the results chapters there is troubling evidence of important assessment information being withheld and intervention not being activated. The exception to this was the rural primary school which opens chapter 5 (Visibility), where parent and teachers are sharing their perspectives.

There are some publicly accessible resources for the legal framework, for instance guides to case law (Wolfe & Glenister, 2020) and various charities who provide online and in-person advice for instance SOS SEN or IPSEA (2021). There are two aspects to note, if the assessment (or refusal to conduct an assessment) or the provision for a child is insufficient it is only the parents or guardians who can appeal that decision. The system is evidence-based and relies upon skills to read and draft documents. Secondly, some of the interpretation of language is highly specific and nuanced. These are significant structural barriers for many parents for a profile which has a high heritability factor, and as Nora noted it took a lot of work for her husband who also had dyslexia-SpLD:

NORA: *Bless him [husband] managed all the paperwork
and everything for the appeal.*

I: It is grinding to do; it's absolutely grinding to do.

NORA: It took up so much time...and [husband] is very good with detail. It took so much of his time.

However, the threshold for securing assessments in case law and in reality is low “whether it may be necessary for special provision” to be made: **RB v Calderdale MBC (SEN) [2018] UKUT 390 (AAC)** (Wolfe & Glenister, 2020, p. 10). Many, though not all, of the children in the study would from the outlines of their situation perhaps qualified for at least a statutory Needs Assessment, which at the least could have provided transparent evidence and guidance to schools and family at no cost to the family. Of those some would have possibly qualified for full EHCP support. Despite the Law offering the one mechanism through both the code of practice and the appeal process to secure support and have their perspective recorded, there was limited understanding of what it offered and how it could be accessed. This was also a finding of the Education Select Committee that looked at the working of the Act and found many areas of concern despite being of the opinion that the changes brought in by the Act were the right ones (Gov.UK, 2020c).

In such a contested space, the needs of hidden disabilities can lack presence. The lack of visibility for dyslexia-SpLD as Oliver reported (“**they said well there’s a lot more children worse than he is**”) adds to the challenges parents face but that does not mean that at the individual level that these children’s needs are any less worthy of having the law applied and support provided.

The accounts of parents’ and children’s experiences in the results chapters make on a number of occasions difficult reading but they are the stories that captured the realities of children with dyslexia-SpLD and their families within education. The lack of visibility of the legal framework contributes to a knowledge gap deficit and the lack of resolution for deficits in literacy access, universal education or inclusion.

The Policy and Financial Framework

Schools are constrained by a range of policy and financial frameworks. They are obligated to have a balanced budget, along with other financial rules (Andrews & Lawrence, 2018). The financial and policy frameworks intersect and as Andrews and Lawrence (2018) indicate, as well as the further work by Hutchinson (2021) and the Education Policy Institute how school based and external features intersect to mediate identification of SEND. This shapes the landscape. For instance, for every child who has an Education, Health and Care Plan (the document that confers legal protection for education needs and support) in mainstream school, the first £6,000 of costs must be met by the school (Hutchinson, 2021). However, the funding received via the funding streams such as the Local Authority would be insufficient to meet that obligation, particularly if a school has a number of such children (National Association of Head Teachers, 2018). This has profoundly impacted upon accessibility of schools to parents who have children with additional needs, as Daniels et al. (2019) identify when they examine the perverse outcomes from competing policy frameworks such as raising attainment, disability and inclusion. Hutchinson (2021) for instance identified that children in academies were less likely than those in LA maintained schools to be identified with SEND, and further the Local Authorities with the highest rates of academisation identified less children by a factor of 11 than those with the lowest rates of academisation.

The lived experience of that contested space is recorded across the data in this study informing the results chapters. Children who are disruptive are an immediate challenge and meeting their needs can be financially taxing if they need individual support, and consequently less obvious needs may fade into the background (National Association of Head Teachers, 2018, p. 3). What is less appreciated though, is that irrespective of funding issues, if a properly formulated EHCP requires that the provision is funded (Wolfe & Glenister, 2020, p. 24) then the Local Authority have to ensure the provision is made; it does not fall onto the school to do so, but the parents may need to challenge non-provision.

The law trumps policy, but policy should be framed within the law, if not it is subject to the risk of Judicial Review. However, some policy is not open to scrutiny or challenge and across the data at regional, local, and school levels this occurred. Guidance to staff on thresholds for assessments can mislead when they appear to suggest that different criteria to the legal tests are operational. For instance the criteria used by Warwickshire County Council (Warwickshire County Council, 2016, p. 8) is an exemplar for many Local Authorities for how they operationalise considering it to grant a statutory needs assessment could reasonably be read to go substantially beyond the legal criteria, and put in place many obligations that do not exist in the law. Which, requires only the possibility, not the certainty of need (Wolfe & Glenister, 2020). Such forms of both official and unofficial policy such as the non-acknowledgment of dyslexia-SpLD as noted by Imogen “**I would assume that’s because it’s not diagnosed locally, parents have to pay for it privately if they want a diagnosis**”, which can be at variance to the legal positions, be less than visible, and make navigating the system for parents and school staff puzzling and incapacitating.

Conclusion

The child with dyslexia-SpLD is reliant upon teachers and parents to navigate the Arc of Education for them. That dependency is seen in ways that extended beyond the typical expectations and experience of other children and their families. Such navigation may also be fully beyond the experience or expertise of the child’s teachers too. Steering a route through mainstream education required that parents and school staff both understood the system that they and the child must operate in. To date there has not been a clear representation of the ways the different structures interact and form a coherent system. The Arc of Education derived from the data in this study is one way of representing such a complex array.

The lack of transparency has created difficulty for both pupils, parents and teachers and schools and some parts of it were misunderstood by all parties. Further, features of the

Arc (such as finance obligations) acted as constraints on education system effectiveness, with respect to addressing the needs of a child with dyslexia-SpLD. Which in turn impacted the form of inclusion that secured the fruits of education. This novel structure answers the first part of Lindsay (2003) challenge to link the within and without factors to describe inclusion. The following chapters describe how the structure interacts with the agency of teachers, child and parents through the lens of the parent perspective.

Chapter 5: Visibility of Dyslexic Children and their Parents within the Arc of Education

Research questions for chapter

The research question for this thesis was **“In what ways do parents of children with dyslexia-SpLD perceive, understand and enact inclusion.”** A reasonable starting point to answer the question is to identify how the two main features that of dyslexia-SpLD and inclusion are perceived and understood by parents and teachers. Dyslexia-SpLD is a name given to a profile of differences (Snowling et al., 2020) which extends across the life course (McNulty, 2003) and has implications for wider health, wellness and economic burden (Carroll et al., 2005; Karande et al., 2019; Livingston et al., 2018; Macdonald, 2012) as discussed in the literature review. Irrespective of whether the wide or narrow definition (Snowling et al., 2020) of the profile is used, there remains a core difficulty in acquiring the fluidity and accuracy required for reading and spelling to enable independent or efficient literacy skills. These difficulties can be exacerbated with the presence of co-occurring profiles of difficulty including those of executive function or communication difficulties. (Snowling, 2013; Snowling, 2005)

The implications of having dyslexia-SpLD are wide in an education system that privileges literacy. For instance, Polychroni et al. (2006) found that academic self-concept was depleted in this group relative to all ability peers except in practical subjects, they did not engage in reading for pleasure, learning was of a surface approach commensurate with low and average ability pupils, and that drive to achieve was external, rather than internal. Given this profile has those ramifications and the absence of ready and easy access to formal assessments (Griffiths et al., 2013), it is important to understand how dyslexia-SpLD is recognized in the classroom. This generates the first sub research question.

- What kinds of visibility of difference and difficulty are observed and understood by parents and school staff for children with dyslexia-SpLD?

Accordingly, this chapter will address what aspects of difference and difficulty of dyslexia-SpLD are most visible to parents and school staff, and what implications that has for successful inclusion. The focus of the chapter will be observed and understood realities of what was observed and understood (providing description at the empirical level) of parents and school staff, for children with dyslexia-SpLD.

The chapter uses case study data from both parental and school case studies, to locate the work within the broader literature discussed with in the review, and with a particular focus on the parental perspective and the persistent across time common account of difficulties as discussed in the literature review (Earey, 2013; Griffiths et al., 2004; Leitão et al., 2017; Lithari, 2019; Norwich et al., 2005; Riddick, 1996, 2010). The chapter interrogates the data and allows evaluation of the degree to which the participant's experiences and accounts in this study reflect the persistent account of parental experiences of difficult with recognition of difficulty and securing support as described previously. This allows for the study to be placed in context. How this study extends those prior findings is by considering both the parent and school perspectives in parallel, through the lens of the parent viewpoint. Studies in the field of inclusion and dyslexia-SpLD have generally taken a school focus and looked at what happens in the intervention or classroom (see for example Griffiths et al., 2013) or collected narrative accounts from parents about the lived experience such as those cited above.

Previous studies have examined the meaning and experiences of children with dyslexia-SpLD in education, and the recollections of adults with dyslexia-SpLD of their own educational experience for instance (Macdonald 2009) This study seeks to extend that by moving beyond description, and using parent and teacher accounts of dyslexia-SpLD and dyslexic children's experiences to understand how they contribute to experiences of inclusive

education for these children. The theme of visibility as the main anchor for analysis is used in this thesis and this chapter is used to explore both the explicit and hidden aspects of a child or parent having dyslexia-SpLD. It extends it by considering what were the indicative causal agents for the accounts given by participants, before further analysis and interrogation of the theme is undertaken in the following results chapters. The sub research question was:

- How can the visibility of dyslexia-SpLD to parents and school staff, help to explain dyslexic children's experiences of inclusion?

Introduction

This chapter captures the key aspects of the theme of visibility and forms the basis for its extension as explored in other chapters. Two forms of visibility were identified. First visibility as observation and interpretation of behaviours, as linked to literacy difficulties. Second, epistemic visibility of the 'others with knowledge or influence' (Byskov, 2020), for example teachers recognising and giving credence to parental knowledge or to other experts.

The chapter is divided into three main sections. Section One (page 163) examines a small group of three teachers and a parent, from phase two of the data collection. It is an exploration of a setting where visibility and inclusive practice were well integrated and the links between theory and practice were explicit. It provided a positive illustration of both forms of visibility in action. Understanding of dyslexia-SpLD and inclusion were discussed, at the school, class and the individual child level. The small group account demonstrated the importance of visibility in reducing distress and risk to all the participants and the child.

Section Two (page 174) considers the evidence from the remainder of the Parent and School case study data. Within the parent case study group were the longitudinal group, individual interviews, and small group interviews. Within the school case were survey and individual interviews of SENCO and teachers and a small group of learning support assistants

and a survey. The aim of the data capture profile was to represent in the study the typical way education was delivered in mainstream education (typical mainstream provision-TMP), and the ordinary (and variable) way education was encountered by parents, referenced as ordinary education (OE). As a counterpoint one family who had used both state and private education was also interviewed, and they represented what Muter and Snowling (2009) identified as parents using their resources when they recognized the system would not meet need. The data collected was located by a range of settings, pedagogical stances and age ranges and broader socioeconomic locations covering the span of education for children aged 5-16 years. Although OE may suggest a uniform quality, the study data captured the known marked regional variability (Johnson, 2020) and individual contrasts, both between schools and within schools (Done & Andrews, 2020; Ellis & Rowe, 2020). Indeed, that variability forms part of the profile of OE and this was confirmed in the recent big data study of all English schools by Hutchinson (2021) which found identification of SEND was dependent upon which school a child attended. This section captures that and describes the lived experience behind the numbers.

Section Three (page 184) considers visibility specifically from the parent perspective as this has been an underrepresented source of knowledge and inquiry in the existing literature although recently there has been some interest in parental contributions (for example Multhauf et al., 2016). The latter considered the effectiveness of a cognitive behavioural program for mothers to deal with the stress of children having dyslexia-SpLD. The drawing on parental accounts of visibility allows for consideration of issues, problems and positive strategies that parents, and school staff engage with the child as they navigate the education system effectively where possible.

Learning from a rural primary school: visibility in action

Overview

The small group was independently constructed by the lead participant Gwen at her own initiative, who had recently completed a research degree and who was the SENCO for a rural primary school. It included three teachers with a range of experience (newly qualified, experienced and SENCO) and year groups (Years 2, 3 and 4/5), and one parent, who had a child with significant dyslexia-SpLD to the extent the school had submitted for a Needs Assessment that was being conducted shortly after the interview. The design of the group was highly fortuitous and helpful, as an external researcher asking for participants it would have been an imposition to request the construction, but it represented an ideal participant group for a form of small group interview.

The evidence from the small interview group generated a layered approach to the examination of visibility. The first stage was to consider what was seen and understood with respect to a specific child. The second stage was what was seen and understood from the class perspective. The third stage from a professional systems perspective. The fourth stage from the parental perspective. This ecological approach reflecting the work of Bronfenbrenner (Shelton, 2019; Weisner, 2008) allowed for a coherent description of the different aspects that are brought to bear on a child's experiences.

Visibility, and what the focus on the single child can inform

The first extract examines how an individual child is located and understood. A newly qualified teacher working with Year 4/5, described her understanding of a child's needs through the actions that she takes and the explanations she offers.

GRACIE: I've got one child who is dyslexic, and his specific need will be that he needs things printed in front of him to have it, because it's

that tracking off the board that is particularly difficult, and the letter formations of words, so having a specific font that he uses to help him just identify the difference between an o and an a, just to see the way it goes. The struggle there is the writing; there's two types of dyslexia you can have, one which is more difficult for you to understand and process, and one that's just more difficult for you to record and get it down.

The account from Gracie draws upon knowledge that the child has a diagnosis of 'Dyslexia', but it is the impact of the child's specific profile that is of interest in this analysis. She identifies three core areas of difficulty: the first is that the typical (efficient) way of communicating information to the class through a whiteboard is problematic to the child creating an obstacle of access. The second is that rapid recognition of alphabetic forms was an area of difficulty, despite the use of an alternative font. That suggested that commonly used solutions had limitations for the individual. The third component is the production of writing, the principal obstacle and there was no apparent solution to that problem.

One way of understanding Gracie's framing of the observed difficulty was that the profile/diagnosis of dyslexia-SpLD comes into being as an 'object', as an outcome when other interventions have not worked. In short it became the explanation. In that respect in the account dyslexia-SpLD was not a description of profile in action but the default explanation or end-point explanation for failure to grasp literacy learning when reasonable efforts and interventions had been put in place (McMaster et al., 2005; M. J. Snowling, 2013; Snowling et al., 2020). It is an explanation rather than a source of further inquiry, in particular around writing. It is interesting to compare this way of thinking about dyslexia-SpLD with the formal diagnostic descriptions discussed in the literature review, (Snowling et al., 2020), many of which echo the idea that dyslexia-SpLD comes into being as the explanation of non-resolution of difficulties in learning to read or write or develop fluency.

Nevertheless, Gracie provided an account of explicit visibility around three significant areas of difficulty (tracking from board, recognition and formation of letters, and writing) that

form the normal way of working in OE and mediate educational accessibility, and there were attempts to address this area within the class. However, Gracie's framing or categorisation of dyslexia-SpLD as two types: one of reading / processing, and one of writing, represents a partial misreading of current knowledge around the profile as referenced in the literature review (Quinn & Wagner, 2013; Snowling & Hulme, 2020). This had potentially problematic implications for the child being discussed and for other children being supported by Gracie as the form of categorisation utilised meant that while there would be recognition of some aspects of dyslexia-SpLD (which would be of potential help), it also constrained what was being acknowledged, because other aspects were not recognised or understood. This lack of recognition was also found in a large-scale Italian study (Barbiero et al., 2019) and an American one (Phillips & Odegard, 2017).

Visibility in relation to multiple children

The next level of visibility is from the class perspective. Children with dyslexia-SpLD in UK in typical mainstream provision are taught in classes with usually around 27-30 other children, (Hutchinson, 2021) comprising of a range of typical and atypical characteristics. It would be expected with this mixed class profile that the children in varying ways make demands of the teacher/staff and the group. The visibility however is within a context of multiple children with different needs and Gabby, who teaches Year 2 and qualified about 5 years prior to the interview, comments on this.

GABBY: I've got the younger ones, it's trying to work it out. Obviously, we've got different children at different stages in my room already. There's some who are just behind on their learning, and there's some who I think there could possibly be something there, so it's trying to identify it early and try to put things in place for them, instead of just going, 'Oh, they've got this, we need to find out what is their needs', so it's that whole individual programme thing.

Gabby's account attests to the dynamic challenges of retaining multiple children's needs in focus and maintaining a coherent group approach for a class. Gabby was dealing with children in key stage one (KS1). As such, the developmental profiles of the group of children would show wide variation. The needs of children with dyslexia-SpLD may only become gradually apparent once they start school and formally start to learn to read, spell and write. However as Muter and Snowling (2009) found in the longitudinal study, parents with insight may have already seen indicators prior to school, as they differentially compared to controls started with early home teaching prior to school start. In that respect Gabby's account is suggestive of an exploratory process in which multiple children's needs must be addressed concurrently and consistent with Assess, Plan, Do, Review as described in chapter 4 *Setting the Context: The Arc of Education* (Arc of Education). That approach as described by Gabby fell under the general auspices of a graduated response, reflecting best practice identified in the Special Educational Needs and Disability Code of Practice :0-25 (Department for Education, 2015).

Visibility – professional systems

The third level of visibility is from the professional systems level where patterns of observations over time and/or the numbers of children with literacy difficulties suggest a need for strategic changes in the school.

In the extract below Gwen, who was a SENCO and Year 3 teacher, reflects upon the limitation or reliance on standard 'evidence-based' approaches (Gwen cited the use of phonics as an example) for children who had not responded to the teaching strategy. In this respect she is presenting evidence consistent with the literature around treatment resistance or non-responders (Fuchs & Fuchs, 2006) and as identified by van Rijthoven et al. (2021). In this extract she describes how a school decision was made to recognise the limitations of the standard phonic approach to the teaching of reading and spelling.

GWEN: ... done, because training's taught people who teach children phonics and they learn by phonics, and they just keep plugging away at it until eventually one day they get it. Well, that is not the case, so we decided that Year 3, no, because that's just making them feel worse. [...] Yes, and that's what we're finding, so we've got to the point where we've said, 'Actually, if they haven't got it by Year 3 and they're not doing it, and they're not having those phonic books because that not interesting to them, and also now with going in...

Gwen was drawing from her professional observation but was simultaneously directly highlighting the gap in others' knowledge around interventions, the need to avoid repeating failed interventions, and that phonics training was not always suitable for all ("**they just keep plugging away at it until eventually one day they get it. Well, that is not the case**"). Gwen also drew attention to the consequence of ineffective remediation of difficulty for a child ("**that's just making them feel worse**"). Again, this is describing a form of visibility not only at the individual child level but as a senior member of the school staff noticing patterns of responses across time, for children with similar difficulties, so representing a different level of analysis. This forms part of the type of data analysis that schools undertake to maintain good quality education as evaluated by Ofsted. There was however limited evidence in the literature around this regarding dyslexia-SpLD; Norwich et al. (2005) for instance undertook a project linked to Dyslexia Friendly Schools and parent partnership but noted that the concept of a dyslexia friendly school with a focus on a specific diagnostic category was at odds with wider inclusive schools' narratives.

The observation of distress with a child trying and not being able to succeed in learning was salient (Carroll et al., 2005; Dahle et al., 2011; Leitão et al., 2017; Muter & Snowling, 2009; Riddick, 2010). The account of consequences for ineffective intervention are recognised as extending beyond the lack of literacy skills. That finding was mirrored in the parental accounts across the data and in the mother Gemma's account following. In the extracts Gwen was providing a rationale for exploring the use of work on real world books and reading (Solity &

Vousden, 2009) as a means of improving accessibility for all children as an alternative strategy for this group.

In addition to exploring alternative literacy instruction techniques the school were also keen to emphasise the importance of literacy more generally, as exemplified by the accounts of how the children developed their own reading groups for play time. This was not literacy as a source of challenge and metrics, but one where the children were engaged for pleasure within a literacy 'community'.

GABBY: *I'm trying to get them off early because they want to read the chapter books. Remember last year all the kids of mine were outside sitting with the chapter books at playtime, because they want to do the same, and they loved it.*

These last two extracts have suggested how a school culture can create visibility and foster learning autonomy. It also highlighted how a lack of literacy skills would be a barrier compounding differences and development. For Gabby there was a temporal gap between her recognition of a need for an additional alternative to phonics for intervention resistant pupils (McMaster et al., 2005) and having the capacity to act within her leadership role. It seemed from her account that it took time and effort to facilitate that change (**"It's taken a couple of years of drip-feeding that idea"**). That neatly encapsulated how visibility was not a common shared phenomenon, visibility was selective and provisional, it was an evolving one in which individuals' position and perceptions was shaped by what counted as valid observation and knowledge.

Across the extracts considered so far, a range of contextual factors occurred, most were behavioural in orientation, some as Gabby's extract above suggests also had epistemological roots, but that was framed within the academic and professional literature. The nature of the child's processing difficulty was just one element that shaped the child's trajectory and their capacity to engage in inclusive education. In the following section a

different form of visibility, that of alternative forms of epistemic understandings and constructs driven by parents is considered.

The making of visibility - the parent contribution

While the teachers considered the matter of literacy difficulties from the perspective of the child as a pupil, the parent considered it primarily from the totality of their child's experience and their own life experience. In the extract below Gemma is the mother of 8-year-old George who attends the rural primary school. Gemma has a strong family history of dyslexia-SpLD and herself went to a specialist dyslexia-SpLD school paid for by her Local Authority. She recognised that George was likely to have dyslexia-SpLD from a very young age. In this extract she describes how she made George's needs visible to the school staff and how George made his needs visible to her.

GEMMA: He is eight. When he started school, I gave the teachers then the heads-up. Then he went to the next teacher, and it's followed-on from each teacher!

I: So how has he been in school then?

GEMMA: [Pause] He didn't like coming in, not that he didn't like coming in, but that was just younger age, but that was just younger age, but he's a very calm, placid child, he wouldn't be one of these children sitting back and be quite quiet, happy with it, 'Oh isn't he a good child', because he's sat at the back, he'll be one of those. But because we just knew he was, we couldn't let him.

I: Tell me a little bit about he's progressed through school, because this is the kind of story of a real little boy in the system.

GEMMA: He struggles, very much struggles. In my opinion he still can't read. He tries to write; he went through a stage of trying to write stories and it was just scribbles. Counting, he can do it but not really do it, to me that's like a reception child

Gemma's account (which was given in front of the teachers as part of a group discussion) was notable for a distinct pause when asked about her son's school experience. This was a linguistic feature which was unexpected from the prior flow of conversation and

was interpreted to indicate that she was considering how to frame an answer. It was also an account of how George through behaviours was communicating his difficulties and need for action. This was an epistemic form of visibility, and not hidden, the school had invited the mother to be part of the small group.

There were sensitivities in both the topic and context of the questions. Both at the time and on listening back to the recording Gemma seemed she was endeavouring to provide authentic answers, but at the same time not to cause offence to teaching staff, who on the basis of this interview were committed to her son and others with similar difficulties; “[Pause] **He didn’t like coming in, not that he didn’t like coming in, but that was just younger age, but that was just younger age**”. A fair reading of her response was she gave an authentic answer i.e. that George did not like going to school, but then engages in a form of social repair to modify her answer and clarified that it was at a younger age, i.e. not now. Her response had ambiguity about whether George was happy to attend school currently. The exchange was illustrative of how parents had to navigate the social relationships of individual staff and with schools, which forms many of the subthemes of parent accounts considered in this section. It also mirrors the implicit findings of Griffiths et al. (2004) who found that mothers reported they used a progressive strategy to engage schools around their child’s problems with dyslexia-SpLD to avoid alienating and generating a blame narrative which could be applied to them, as well as to maintain engagement. From a research perspective it was an unusual direct example of the nuanced usually non-visible power relations that exist within an educational structure, and which permeate all the parental accounts.

In the extract Gemma described how she was active in making George’s needs, as she understood them, visible to each of his successive teachers. Also, how she recognised her child was the kind who could be overlooked (“**calm placid child**”). This draws out two aspects of visibility. First, the capacity of others such as parents to recognise and communicate important

information about the temperament and difficulties experienced by their child, for example **“calm placid child”** and **“In my opinion he still can’t read”**. Second the degree to which the child, parent (or others) had presence or were acknowledged by persons within the education structure, such as teaching and support staff. For George there was a continuity of visibility as each year Gemma ensured the class teacher had what she considered relevant information, and the implication was that her knowledge was recognised (**“I gave the teachers then the heads-up. Then he went to the next teacher, and it’s followed-on from each teacher!”**).

In Gemma’s account she describes a form of risk where needs could be overlooked, resultant from a lack of visibility in the class as a whole **“because he’s sat at the back, he’ll be one of those”**. The implication was his needs could be minimised or missed when attentional resources had been directed at other pupils in the class, such as those with behavioural challenges, was picked up from the initial phase one school survey. The competition for attentional resources was also one which as Gabby identified in her extract is a dynamic of the setting. In Gemma’s account she sought to be her child’s advocate and ensure his needs were visible to be actioned.

However as will be later discussed in chapter 6 (Discontinuity-Disjuncture) the child’s presence in a class may also be noted by other children in favourable or unfavourable ways that created opportunity and vulnerabilities with both Lauchlan and Boyle (2020); Riddick (2000) capturing evidence around how children can create the circumstances of stigma without recourse to labels, or repurposing the ones available. An example of this addressed in chapter 8 (Illusion of inclusion) was when one of the parents (Nora) reported her son’s comment **“but he said ‘you know, they can’t help it mum because they’re special’”**. The exchange also captured how Gemma perceived the extent of George’s difficulties **“to me that’s like a reception child”** placing him in a developmental category at variance to his peers and suggesting minimal progress. That may have been a challenge to the school to hear given

the efforts they had extended, but they did not reject the observation. This was an account of specific differences in development, one that had a temporal dimension. It was also a different formulation of visibility, but one the school seemed to acknowledge and value.

The nature and types of visibility in a rural primary school - a summary

In the four accounts from the small group, different forms of visibility were articulated across the arc of primary education. There were both behavioural and epistemological forms of visibility, and across the school and in the case of George they were used in combination. In this case the school listened to the mother as she sought to make George's needs and risks (as she understood them) visible, and to incorporate this knowledge into their work. They were advantaged as a staff group by having a SENCO who had from this evidence, a sound 'theory-to-practice' framework. She referenced literature, had good grasp of research for the area of work, and she was able to critically appraise the research and had familiarity with key authors' work for example (Solity & Vousden, 2009).

Of all the staff interviewed across the larger study, she demonstrated the clearest account anchored in research of knowledge and understanding around dyslexia-SpLD. However, in that setting she was not alone, Gracie referenced her dissertation and research work too, so this was a school setting where post-qualification development at a higher level (rather than same level and extending laterally) had taken place. Leitão et al. (2017) study had identified how variable pupils' experiences were with teachers, and to this extent the quality of knowledge a teacher can draw upon will have an impact on their own delivery and, through dissemination, that of others.

Despite staff expertise and parental efforts, there were still challenges that reduced how visible children's needs were within a class setting. Gemma's account of George showed

how he could make himself relatively invisible by sitting quietly and hiding at the back of the class, despite the fact he was struggling but that invisibility also extended into home:

GEMMA: *yesterday they did the Stone Age. ‘What you doing?’ I got more information from the school this morning than I got last night, even then I didn’t... he doesn’t give that out freely.[...] Because he’d rather just watch telly, or he’d rather just give a quick answer, and I’ll stop asking questions.*

The disengagement by George could be attributed to his overwhelming difficulty with dyslexia-SpLD, the fatigue resultant from having to expend additional effort to meet basic demands, and the presentation of lower-level anxiety and depressive features (Carroll et al., 2005). Further, Gabby’s account also highlights how there are multiple demands on the classroom teacher and while teachers may recognise that a child has needs, it can be challenging to pinpoint a specific underlying cause. For example, there is significant shared crossover for features of a variety of Specific Learning Difficulties, that they may co-occur, and they may become evident over a span of time (Landerl & Moll, 2010; Willcutt et al., 2019).

For Gracie, Gabby and Gwen there was also value associated with a particular form of visibility, that of diagnosis. This was despite some recent commentary on its lack of value (Lauchlan & Boyle, 2020). However, while the staff in the school focused on the child or children and developed alternative helpful strategies such as non-phonics reading instruction techniques, there was no sense of how this kind of quality work fitted into and supported a child across the Arc of Education, into senior school and beyond, and this segmentation by phase of education or institution was a feature that is replicated across all the data.

One of the qualities of the rural primary school small group was the level of mutual emphasis around inclusion as meeting the child’s needs and the way both forms of visibility, behavioural and epistemic were brought to bear in securing it for a child or children. However, it was also within the context of meeting all children’s needs and creating a sense of

community, illustrated in the children reading at playtime. To that extent the school was demonstrating different levels of the Göransson and Nilholm (2014) framework for inclusion but it was not uniform to the setting, rather it was dynamic and reconstituted each year as captured by Gabby **“Remember last year all the kids of mine were outside sitting with the chapter books at playtime”**.

The group was from a smaller school in a rural area. There was a coherence in the group account. However, this was a self-selected group who were willing to participate with in-depth discussions. It provided a comparator and contrast to the data captured in the school survey and in other teacher accounts which took in a wider range and number of staff and with the parent case study. The small group allowed for the complexity of the various interacting systems and agencies that impact upon inclusion for a child with dyslexia-SpLD to be made visible. It was placed at the head of the results section because it presented as something of an outlier in its strong theory to practice link not only at the child level but also at the class and systems levels; the use of both behavioural and epistemic visibility provided a point of contrast as well as similarities to the rest of the data within the school case study.

Issues of visibility in schools: the typical account

The rural primary school provided a window on what was possible to achieve with respect to parent engagement and inclusion for children with dyslexia-SpLD. The next section drawing from the rest of the case studies provides an insight on OE. They represent the pattern of typical accounts consistent with the literature covered in the review, describing a range of factors that are known to impact upon literacy skill development such as economic status, home literacy environment and quality of teaching (Griffiths et al., 2013; Johnson, 2020; Van Steensel, 2006).

What this study does is move beyond general findings linked to categories of difference such as SES to generate explanations that could account for the high level of reproducibility of difficulties and differences that cross geographical boundaries and systems. To do this the case studies were composed of mixed factors which included those identified influential categories, not as a representative sample but as purposeful one. The first stage was to examine the quality of visibility of dyslexia-SpLD and inclusion understanding. This was a new form of inquiry extending the literature.

In the first section Fraser's account provides insight to the observed realities of how home circumstances and limitations of resources within the school setting impact the visibility of children's needs. Fraser worked in a locality where social and economic challenges like those identified by (Johnson, 2020) were the dominant part of the community landscape.

The constraints of parental skills & and teacher time on creating inclusion

Fraser, who had been qualified as a teacher for around 5 years, worked with Year 3 in a large primary school located in a socially challenged area. In the following extract he comments on complexity of family history, context, and the realities of visibility and delivery of education. The section on literacy has been underlined for emphasis and placed in context of the rest of the response. There is a degree of sadness in both the telling by Fraser and in reading of this account, of a single mother having to learn to read, and unable to help her child.

FRASER: There is only so much you can do in five hours in a school day. You do need that parental support but we've parents here who can't read themselves, so like a child in my class, he's not dyslexic but he has very poor reading and his mum can't read either so she's.... I think she is currently taking courses or lessons to do it but then of course you have the whole issue of setting him homework and there's no point because there is not help at home. She's a single mum and there's no one else to ask, so there are quite a few situations like that parent-wise so it's a bit of an uphill battle.

Comparison can be drawn between the parent Gemma (in the previous section) who did get help during her school years that had meaningful impact, and a mum who did not; around how the shadow of remediated or unremediated literacy difficulties shaped intergenerational transmission of risk and difficulty (Hamilton et al., 2016; Muter & Snowling, 2009). Gemma was able to act as an advocate and provide support to George. She had the benefit of support when she was younger, but the mum in Fraser's account was not able to advocate in the same way and not able to help her child. Fraser had information about the specific context, further that this was not an isolated incident in his class, and to that extent there was a form of visibility.

Difficulty and debate for visibility and recognition of diagnostic features

However, there was also the challenge of non-visibility when he comments on the child "he's not dyslexic" which given the history he presented raises questions about how Fraser understood the term "**dyslexia**" within this context, and on what basis the claim that he was not dyslexic was made (given no reference was made to formal assessment). Later in the interview Fraser references his recognition of dyslexia-SPLD based upon children who had been previously diagnosed "**children who were diagnosed with dyslexia I see similar traits with**". So that diagnosis provided a benchmark category that allowed an implicit understanding against future judgments. That understanding also had implications around expectations of children's function and progress as well as needs. The impact of confusion around a diagnostic term (what constituted dyslexia-SpLD) that had become and remained in some quarters contested (Kirby, 2020a; Snowling et al., 2020), appears to have seemingly added to the confusion. This is illustrated by the extract and how it links to his identification of the category dyslexia-SpLD and what knowledge of resources he was drawing upon to make decisions in this respect.

The effect of that contested understanding for communication, actions, allocation of resources, around whether or not a child has a diagnosis or what the nature of the problem is, and conflict between parents' capacity to meet school expectations occurred at several points across the parental case study. An example of the friction arising from the data was Yvette's account of the difficulty in securing support for her son Yves. The heart of this dispute was in the explicit social visibility of difference and difficulty and the way labels were perceived to limit or extend the identity. This was school staff directly challenging a mother, and implicitly by their account making claims of her generating harm to her child, by seeking to secure a diagnosis (label).

YVETTE: To the school I think I find it quite shocking that they've said something like why do you want to slap a label on your child?

From Yvette's account, that form of visibility, i.e. a diagnosis was regarded as harmful by the school. The issue of labelling as a barrier to inclusion is one found in the literature (Lauchlan & Boyle, 2020), particularly those focusing upon behavioural aspects advocating for universal solutions to intervention for dyslexia-SpLD (Gibbs & Elliott, 2020). In this respect the school staff were denying a mother's knowledge and authority and could fairly be described as a form of epistemic injustice (Byskov, 2020) a significant feature across the parental case study.

In contrast to the school's view, Yvette's personal experience of diagnosis was of the positive value of it with respect to understanding the lived experience. As she noted **"I actually said, because my brother's got Asperger's and he wasn't diagnosed until he was in his late twenties, and he said for him it was a massive relief just to understand why he was different."** Yvette did manage to secure a diagnosis later on, but it was in a different school and remained an unresolved conflict with the first primary school. She reflected on the value of that form of visibility and its wider framing for Yves, where in many respects it could be seen

that she was creating for him a different form of inclusion, one linked to others like him, across the ages:

YVETTE: *Yeah, well we spent a lot of time with Yves going through famous people who had been dyslexic and trying to say actually it's a gift in some ways, and really try and take a positive approach to it, and he was markedly better after he had the diagnosis.*

The contested space of diagnosis, while notionally about identity, was also about the depth and density of the visibility of difference and difficulty. Recognition placed obligations upon the education system as discussed in chapter 4 (Arc of Education), and the school's perspective was of universal provision as Yvette commented **“but there wasn't clear differentiation or anything like that”**.

The nature of the academic argument about the relevance and use of the diagnosis of dyslexia-SpLD or similar outlined in the literature review had for Yvette and other parents in the case study moved beyond an academic argument. It had implications in the real world of parents and teachers, and how they navigated the space of their own and their child's visibility, as well as recognition of the problems a child faced. From Yvette's description, which reflected other accounts in the parental case study, diagnosis mattered to parents because it provided an explanatory framework for the child and a mechanism to situate lived experience in wider accounts of difference.

[Link between skills, formation of inclusion and location of learning](#)

In Fraser's opening extract, he provides an account of the development of reading skills beyond the classroom and extending into the home **“you have the whole issue of setting him homework and there's no point because there is not help at home”**. This provides further evidence around the permeability of boundaries and geographical features of inclusion. Two aspects are conveyed in that extract. Firstly, that there is reliance by the class teacher/school on parents to engage in activity directed by the school to support skills. Those

skills are ones that mediate both local and long-term inclusion. With that is a presumption of parental skill. By implication, variability in the home setting is likely to impact on securing progress and how cohesive the class can be as well as the workload added to the teacher to fill in gaps. This was an area addressed by Ellis and Rowe (2020) in their large-scale study seeking to reduce gaps in literacy between pupil groups.

Secondly, the mother referenced (by Fraser) exhibited a level of courage in trying to address her literacy difficulties, but in the account there is no evidence that the school are optimising that and securing both the child's and mother's skills in tandem; for instance understanding what skills she was learning that she could reinforce. There seemed to be a barrier about differing worlds as described in chapter 4 (Arc of Education). Again, this raises issues on the nature of visibility. Rather, there was resignation by Fraser that there was little point sending work to be done at home. Overall, the implication was that an important aspect of inclusion for both child and parent was compromised through disjuncture between school and home. That point is expanded upon in chapter 6 (Discontinuity-Disjuncture). In those situations, it fell to the school to secure long term social inclusion at the end of the Arc of Education. That was contingent upon the kinds of progress that secures core literacy and mathematical skills, as Fraser noted:

FRASER: *we'll have intervention groups set up to try and get them back so they're not dropping behind [...] especially at this school the children come in at such a low start point anyway, so you're always catching up*

In that respect visibility was at the wider social and group level which as the next section examines places unequal demands on teachers and between schools with respect to the non-financial resources to support the child.

Resources, visibility, and fairness the challenges to delivering inclusion

Fraser mentions there are several parents in similar positions (suggesting low levels of literacy for parents) and he conveys a sense of forbearance when he talks about ***“There is only so much you can do in five hours in a school day”*** and limitations of attentional resources, time available, demands and educational and social resources to meet the need. In this respect Fraser is echoing the multitude of demands found in the school survey and in other teacher accounts, which describe their overloaded schedules, hidden from view of parents and children; for example Hara a maths teacher working in an urban senior school

HARA: No, no.... we have 50 lessons over two weeks. So, we have a two-week timetable, we have 50 lessons and I only get five [preparation for class hours], so I teach 45 lessons.

The repercussion for children who are not able to be supported at home has wider impact on the class functional cohesion. Part of the implicit partnership with parents that teachers depend upon to maintain momentum and progress in the class will be disrupted. From a school’s perspective then, academic aspects of inclusion are reliant upon activity in the home. Staff will often adopt a category approach to allocating children to different ability-level groups for ease of management (Smale-Jacobse et al., 2019). However, there was also recognition in the system of the importance of the home setting for children’s outcomes as indicated by the following extract from a class support staff member. In the extract MAP is Middle Attaining Pupils, and LAP is Lower Attaining Pupils, which conveys the salient way visibility of children are understood at the group level, and how they are located within the school system.

Higher Attainers generally progress well and the middle attainers with strong parental support make good progress. Children with little support from home (about 15%) tend not to progress as well as others when they fall into the MAPs minus and LAPs groups. The school meets the social and emotional needs of most pupils well.

(PT05 Class based support staff)

Much of the material considered so far has pointed towards group level visibility, and that is the dominant aspect in the school case study. But at the class level teachers may recognise differences. To close this section an extract from Fraser is used to highlight the common position on understanding dyslexia-SpLD of teachers and parents, the discrepancy between verbal skills and capacity to write.

FRASER: *I think what it was that really flagged it up is that they're both, when you talk to them verbally, they've great ideas, you know, they can tell you, if you're writing a story for example, they can add bits to it, they're very good verbally but as soon as it comes to writing it down though it is kind of ...*

Although there were exceptions as illustrated previously in the school case study, staff generally considered matters from the perspective of the class or group level as in the example from a Qualified teacher (PT71) in the school survey in response to a question about children who have the biggest impact on the class: **“Children that can work independently and can even support others (LAPS) Sharing of good ideas”**. There was in this account a degree of homogeneity for the group which was focused upon observed attainment not on potential. Yet as Fraser noted the above discrepancy between potential and attainment was an important indicator of dyslexia-SpLD. The section has endeavoured to capture some of the complexity and competing demands that school staff particularly teaching staff face as they seek to provide quality education under sometimes very challenging circumstances at a group level, but also how the limitations in knowledge led to informal heuristics which were not readily open to evaluation. Those factors and the environment of schools were rarely visible to parents.

Invisibility and personal knowledge: parent and teacher accounts

The nature of invisibility as reported in the data extended from non-recognition of core features of the profile that generated risk, to the seriousness of failure to recognise a child's persistent observed difficulties and the psychological and emotional consequences. Both had implications that linked to the quality of school staff and parental knowledge. Compared to well-established and publicly accessible information about dyslexia-SpLD, across the available data, both parents' and school staff's understanding of the condition had many gaps and misunderstandings, and on occasions was non-existent. The degree of deficiency and lack of depth of knowledge was to be expected in the parents' case study, and parents in varying ways made attempts to fill the gaps.

SUSAN: *I then went through the route of reading up on all the things. I thought has she got ADHD, whatever because she had some terrible temper tantrums at home but was really good at school and then I asked the school to test her. I said I thought she had dyslexic tendencies*

But the degree of lack of knowledge was a surprising finding in the case of school staff. This was exemplified by a parent report of a comment made by her child's teacher:

TRACY: *not even a basic knowledge, I've had people ...I had one teacher say I've been teaching for 15 years and I've never come across a dyslexic...*

While this may seem extreme, Frank's responses to questions about his understanding of dyslexia-SpLD give insight:

FRANK: *I have had no training on this ever in 20 years of teaching, so you can see it's hard to get training these days.*

The value of collecting both parent and teacher accounts was it allowed this kind of cross-reference. The issue raised by both extracts was important in that the visibility of children with dyslexia-SpLD would have realistically been muted (or in the worst case as

reported by Tracy rendered invisible). If teaching staff do not know what they are looking for as indicators of the profile or recognise the need for prompt action and critical evaluation, then their agency would be constrained. The advantage of sound knowledge (or at least timely access to it) was well described by Gwen, Gabby and Gracie in the segment that opened this Chapter. Frank understood it was something to do with reading or writing, that presentation could be different for each child and that older children could develop adaptive strategies. So, he had a basic grasp, noting it was a **“problem with words and language”** but the knowledge about the contributing causal mechanisms or importantly interventions was absent. This was a point of interest as he himself described having literacy difficulties as a child and being in the ‘special class’.

The data in this study suggests that hazy or incomplete understandings will impede visibility at the behavioural level but also at the epistemic one too. This is reinforced across the school survey when questions were asked about factors that had impact on inclusion, there was only one reference to dyslexia-SpLD, of having had an impact on inclusion, **“dyslexics with poor working memory”** (PT41 teacher), providing the first early indication in the research study of how visibility or lack of it was a salient factor for the difficulties reported by parents.

The value of the school survey was highlighted when it was possible to gather the views of a majority of staff in one setting. When staff in the school were asked to identify (for those they worked with) what the social and academic needs of children with SEND were, only 4 of the 42 respondents made direct reference to literacy processing issues, but those references demonstrated clarity of insight and knowledge which was not limited to qualified teachers age-related expectations (ARE). As below:

It depends on the nature of SEND. The prevalence of children with difficulties in spelling is the highest. Letter formation is also poor. 1/3 children struggle to be at ARE in phonics by the end of Year 1 and this is

an indication of the difficulties they will experience as they move through school.

(PT10 Class based support staff)

The importance of this finding was that for the dyslexia-SpLD profile, knowledge and insight are not necessarily linked to status within a school, and this is relevant, as much work with children who have literacy difficulties and dyslexia-SpLD will rely upon support staff. Secondly that the recognition and presence of dyslexia-SpLD/literacy difficulties by staff is somewhat binary, staff seem to either have interest and knowledge and across the data they remained a small minority or they do not register it as problem, or have very limited understanding, which makes for uneven learning experiences for the children as they pass through the Arc of Education.

The parents' case study account

Visibility of intervention benefits and the iatrogenic impact for a child

Parents (unsurprisingly) in their case study were generally concerned at their own child's level and more muted about categorisation relative to other children, but not about the matter of diagnosis as illustrated by Yvette's comment previously. The divergence with the school was illuminated when general strategies aimed at the class group or group with difficulties were applied, rather than specific or customised ones for a child. This resulted in further failure by the child to make progress, or a failure to decide on a concrete description to account for differences. Those themes are a leitmotif through the data and will be illustrated through the subsequent chapters. The following section will develop the counterpoint description of visibility from the school case study.

Visibility of intervention: a focus on the specific child, the impact of interventions

One of the ways of delivering support was individual or small group extraction, where children were taken out of class in small groups or 1:1 to receive targeted support. There

remained in the data conflicted views about the merits and value of the approach and the way it was implemented, for example Tracy's comments on Thomas's provision "**he's being pulled out of citizenship classes and he's done paired reading for a term [...] I'm so embittered by the entire education system**". The dominant support provided to children with literacy difficulties was through small groups and class extraction, but most parents including Tracy at some point stepped into secure additional one-to-one private individual support, out of school hours to supplement the school provision. The remainder provided additional support at home. The actions by the parents spoke to a visibility of observed difference and difficulty and its wider ramification.

The alternative strategy was to provide designated support in class. Nevertheless, there were drawbacks with this form of intervention. In the next extract Gemma reflected on her own experiences of been extracted from class and having a teaching assistant to support her in within it. This shaped her view of the type of support she wanted for her son.

I: So, from that, I gather that you got taken out of class rather a lot? [...]

GEMMA: I didn't enjoy it, and I had a teacher that was always sat next to me, so you couldn't do silly things, like you couldn't mess around; not that you mess around, but just little things...[pause]

GEMMA: Just be a kid. [pause]

GEMMA: Just be a kid yeah, because I always had somebody sat with me, nobody wanted to mess around with me, so you don't want that all the time.

The text through **[pauses]** conveys some of the challenge Gemma had recounting her experience as a child. The last sentence of the extract is used here to illustrate a particular form of visibility, of a child's world. Her contribution was in articulating something that from the data was overlooked in providing support, how it impacted upon the social relationships and perceptions of others. In this case it illuminated how children have their own private

worlds and memberships. First, these may not be visible (indeed being out of sight to be able to “**mess around**” was a salient feature as suggested by Gemma). Second, adult strategies designed to resolve a problem of difficulties with literacy from this may inadvertently create risk of collateral psychological and social damage, that are often largely invisible to staff; for instance, Xavier reporting on his daughter Xara taken out for literacy support referenced she was “**she’s clearly aware that she goes to ‘the group of the dummies’ as she says**”. That Gemma was recalling a painful memory from primary school, from many years earlier demonstrated how the shadow of inclusion difficulties in the early phases of education had pervasive impact, pointing to the relevance of this study. Key to that was the issue of visibility of a child’s world.

Symptomatic vs specific intervention: accommodation or remediation

There was another approach to supporting children with dyslexia-SpLD which has been alluded to by Yvette in the previous section, which could be characterised as symptomatic/surface management, one focused upon adaption rather than remediation. It was one in which generalised approaches or strategies were used to address observed literacy difficulties, and where diagnosis and the accompanying data were backgrounded (Gibbs & Elliott, 2020). In the following extract Karen discusses the implications of this approach and the difficulties it gave rise to with respect to visibility.

KAREN: [...] They said, “he doesn’t need to be assessed because we’ve put everything in place as if he was dyslexic.” They had screened Kevin and put these in place. I thought that was really good and I’m really pleased, and one teacher was fantastic, and she got him a laptop and stuff and they were doing sessions to help him learn to type, brilliant.

Skills teaching in the use of technology is generically useful (O’Connor et al., 2018). Specifically, it represents a way of overcoming barriers related to literacy from the normal way of working in a classroom as described by Yvette. It facilitates a level of independence beyond

relying on personal support, such as having a learning support assistant to scribe. It is, however, observably different from the normal way of working and can mark children out. In the following extract Parent 7 described another form of visibility in how her son was reluctant to use equipment:

I think this school, bless them, they really picked up on his needs and when he was trying to hide things or not work a sensible way or not use the laptop, they basically turned round to him and said do you want your GCSE grades and he's like yeah and they were like, you're going to have to use everything that's been given to you, you're a bright kid you should use it, you must use it and it's perfectly alright for you to use it.

Part of what was being addressed in the account was how meeting the outcomes can be done multiple ways, but that doing everything the same way would lead to individuals experiencing disadvantage over the longer term. So this was an account about being the same but different, an important aspect of individual identity.

Failures of visibility in action the case of Karen and Kevin

The two types of visibility illustrated in the previous extract are the child's sense of his visibility to peers and recognition of his difference, along with observed problems of not effectively engaging with work by the learning support assistant. Technological solutions also have impact across the Arc of Education if followed through. However, such approaches do not fundamentally alter the underpinning skill and deficits profile, which would be unique to the child; they are accommodations not remediation. This became apparent as Karen later recounted, following Kevin's transfer to high school.

KAREN: So, for example when they are given homework [...] but he had to write it down. He couldn't write it down. He couldn't copy off the board or if he did he couldn't read it back to himself. Or he couldn't finish off writing what was down from the board there.

So, in this respect the primary school's strategy of 'putting everything in place' had not worked, he remained observably disabled relative to his peers. Nor was the use of technology carried through. That arose because the basics for accessing education over the longer span of the Arc, the ability to read and write independently commensurate with peers, had not been secured sufficiently for him to access the curriculum in the next phase of his education. In Kevin's case visibility was muted because individual assessment and associated analysis, and remediation had not been done or put in place, only some form of screening (but no detail offered). As Karen recounted (in a way similar to Yvette), the school were not engaging with her account of the degree of severity of Kevin's difficulties and its potential impact in the next phases of the education. Indeed, she details in the interview her many attempts to get them to assess Kevin, and their reasons for not doing, she concluded their resistance were based upon finance and resources constraints, when they kept telling her:

KAREN: *They said, "you can pay for it yourself", and I thought, I could have paid for it myself and I would have but, I just felt, and I don't know if this is true or not, but I really felt I wanted it to come from the school. Because I felt I would be classed as some middle-class mum whose child was underachieving and I just felt strongly that it would hold more sway if it came from the school*

For Karen, a key challenge was that school staff did not seem to understand dyslexia-SpLD for Kevin specifically, as well as the general nature of dyslexia-SpLD. Despite the claim they made to her that they did not need to diagnose 'it' (not defined) as they put everything in place as though he had it (not defined), they pursued lines of action that did not address Kevin's needs or plan for transfer, and which reasonably should have been visible to them.

It did not occur to Karen that the school may at a philosophical level not accept that dyslexia-SpLD was a 'thing' or the implications of that, and yet her account of the school's actions is consistent with those in the literature arguing for non-diagnosis and universal

provision. Karen had insider knowledge about school attitudes, and her extract illustrated another aspect of visibility, that of privileging some sources over others. The outcome was the school resisted making fully visible Kevin's difficulties through documentation and assessment until the point of his departure, as she describes in the following truncated extract:

KAREN: *Then I thought, it's fair enough here, but when he gets to the next school, what's going to happen. [... details out efforts...]*

So, I asked them [...about formal assessment] and eventually, they have a got a really good teacher and she said that she had got them to do it but, it could take eighteen months. I said "look, as long as it's done by the time (leaving point), as long as it is done". Anyway, they did, they did push it through and got him done for then. The Educational Psychologist was brilliant, I nearly cried. You will probably be having me crying here.

Features captured in Karen's account were across all the parental interviews in one form or another. There were persistent strands for all the elements of visibility presented above; those of parental recognition of problems with literacy, relationships with school, difficulties in gaining clarity about the nature of the problem, privileging sources of information, the lack of timeliness or urgency, child making progress or not, the focus of schools on their territory and zone of influence rather than the Arc of Education, and contested understandings of what the problems and solutions were, along with ineffective application of intervention. Karen's account synthesises them into a compact narrative. In the next chapter Karen's experiences again are features to illustrate a particular form of visibility-discontinuity.

Implications for inclusion

At the start of this chapter a sub research question was posed:

- How can the visibility of dyslexia-SpLD to parents and school staff, help to explain dyslexic children's experiences of inclusion?

The chapter addressed this question by identifying two forms of visibility, behavioural and epistemic. It considered the contrast between a single setting where both forms of visibility were brought to bear at a child, class, and systems level; with accounts from other settings that reflected TMP and OE. By contrasting the single with the broader account, and the internal contrasts within the parent and school case studies, several contributing causal features located by both forms of visibility were identified. These covered issues of what knowledge was available and how parents and teachers understood dyslexia-SpLD including their value of diagnosis, and how that linked to different forms of intervention. It illustrated relationships between school staff and parents, the risks associated with intergenerational transmission, and the wider social context both outside and inside the classroom and school. Within the school the study identified the tension between maintaining cohesion in class and specific support, visibility of differences to peers, effectiveness of interventions and their universality or not. This was against a background issues of uneven resources including parental support, and fairness in a pressured system. There was also the nascent account challenging the idea of inclusion by physical proximity as the only or best form of inclusion in education. All of these were identified in the data as disrupters to a child with dyslexia-SpLD experiences of positive inclusion.

The interviews with parents expressed the profound distress experienced by their children and by them not only on behalf of their children but also due to frustrations with relationships with school staff, delays with diagnosis, inadequate interventions etc due to lack of visibility. Often this distress was anchored and arose from the children being out of step with their peers.

Although the range of responses varied across time and setting there was a pattern. Primarily problems were observed in literacy, as it formed the core business of education, and was recognised by parents as important. However, the problems were not confined to that

area, they were not circumscribed as the name specific literacy difficulties may inadvertently suggest. Parent 10's child's stresses around school compulsory swimming lessons when they were in Year 4 gives some indication of how cumulative pressures around accessing education (which was for them mediated by literacy skills and self-organisation) can become exemplified by a totem task, in this case swimming. In the extract below Parent 10 elaborates upon a question of "How did [their child] find going to school?"

Parent 10: *So, [they'd] often wake up on a Sunday night and be violently sick in the middle of the night, or be inconsolable, wouldn't stop crying and shaking, couldn't speak. And we ended up missing a lot of Monday's. And then, obviously, I get the snotty letter saying that [they] had too much time off school, and yet they wouldn't do anything about [their] swimming, or at least move [them] up with [their] peers but in the lower group. But there's no help, no feedback. As I say, [they] used to talk about killing himself, and -*

I: *How old were they when they was doing that then?*

Parent 10: *[They] was in Year Four. So, I mean, I went into [their] bedroom and [they were] there once with [their] hands round [their] throat.*

Having difficulties with a sport task in not of itself enough of driver to want to kill oneself or die as an 8-year-old. The wider context is the degree of vulnerability the child had, that then led to aspirations of self-harm. It was a very direct form of communication. What was also salient was the degree to which there was a failure of recognition, or appreciation of the importance, by the school of the relevance in the different forms of communication the child and parent were using (epistemic visibility). They were failing to make use of that information and this meant the negative trajectory was exacerbated. Visibility then, was more than just seeing a behavioural difference, but also about the level of investigation of factors creating the difficulty leading to difference, and what might be required to alter trajectories of development. Such inquiry had the potential to disrupt 'normal ways of working' by prioritising the need of a specific child, rather than prioritising the group. Recognition created the need for

action and working against the normal way of doing things to address barriers to learning and inclusive education.

In the case of Gwen the SENCO, her recognition of a need for an additional alternative to phonics for intervention resistant pupils, it seemed from her account to take time and effort to facilitate that change and that system inertia played a role. **“It’s taken a couple of years of drip-feeding that idea, because it hasn’t always been... well because obviously other people have different experience with different”**. However, that time to make learning difficulties visible meant individual pupils’ access and educational experience was less than optimal. Seemingly from this studies data there is a level of structural inertia, that serves to deliver education efficiently, but works against the agility required to ensure children with dyslexia-SpLD access education effectively and that both forms of visibility behavioural and epistemic are important in facilitating the release of the embed inertia.

One of the curiosities in these findings was the manner in which so many factors shaped a child’s literacy and learning trajectory, and onwards to their experiences of inclusion, and yet the dominant focus in literature for dyslexia-SpLD, has been on the individual differences in processing letter sound correspondence and the substructure of those individual differences (see for instance Carroll et al., 2016; McGrath et al., 2020). The implicit assumption was not only were they causal to reading and writing difficulties, but that resolution of that problem would resolve the contingent difficulties linked to poor experiences of inclusion as well (Polychroni et al., 2006).

However, the analysis of data pertaining to visibility has shown that while improving literacy does help; the causal features that give rise to what experiences a child with dyslexia-SpLD has of inclusion are myriad. This broader issue of complexity around inclusion was raised as a challenge by Lindsay (2003), but the examination of those factors and particularly for children with dyslexia-SpLD has not prior to this study been directly addressed. Linked to that

was risk to inclusion, educational outcomes and life chances for the children, their families and indirectly, to the school. In summary the heavy focus on strategies to raise literacy attainment through intervention for children with dyslexia-SpLD have not of themselves resolved the problems, which suggests that a wider perspective was required.

Across the extracts considered so far, a range of concurrent contextual factors occurred, the nature of the child's processing difficulty was just one element that shaped the child's trajectory and their capacity to engage in inclusive education. This chapter has considered visibility from two stances, behavioural and epistemic, and the ways in which both forms made explicit or muted difficulties and challenges to inclusion across a range on contexts. In the next chapter the issue of visibility is reconsidered in further depth from the perspective of a continuum of disruption to function before being subsequently considered from the agency perspective.

Chapter 6: The significance of Discontinuity and Disjuncture in the practice of inclusive education

Introduction

The previous chapter examined what kinds of viability of difference and difficulty were observed by parents and school staff for children with dyslexia-SpLD and concluded that the failure to resolve the problems over sustained time suggested a wider perspective on identification of barriers was required. This chapter is the first of three that reconceptualises the theme of visibility as initially described in the last chapter. The chapter considers a form of visibility linked to disruptions, the one after considers visibility linked to agency, and the final one linked to construction of inclusion. It does this by considering not just the description of the context of parents and teachers, but how events and situations could be grouped together, illuminating a structural framework. That allowed for two other forms of visibility for the researcher: one, the mechanisms by which difficulties arise or were mitigated, and secondly the nature of the events that gave rise to difficulties. Through this higher level of analysis, interrogation of how dyslexia-SpLD and inclusion are experienced, perceived, and enacted can be critically evaluated.

A starting point for this chapter is the observation that the natural world contains continual disruption, uncertainty, and unpredictability and so the ability to handle as unexpected or spontaneous occurrences are markers of human creativity and resilience (Metzl & Morrell, 2008). It follows that the capacity to effectively accommodate challenge and disruption forms part of the natural and essential architecture of learning and development. Martin (2013) examined this through the lens of academic resilience and buoyancy and the factors that shape it, developing a measure of assessment to use with

pupils. To that extent the typical disruption occurring in the education system is part of the (very) hidden curriculum of life skills learning for pupils. An important part of that resilience was the development of a sense of personal confidence built upon a bedrock of skills (including literacy) that could be brought to bear in class based and other situations. Lithari (2019) examined how differences in expected skills level impact upon self-perception, which also links to resilience. In her study she reported on 6 secondary school children and 4 young adults she interviewed along with an experienced SENCO. She explored how children make comparisons with peers and this includes academic skills of reading and writing and function that contribute to a fractured academic identity.

In this chapter, I will argue that individuals with dyslexia-SpLD are both less able to deal with day-to-day disruptions and be at greater risk to experience major disruptions with greater consequences additional to those for most typically developing learners. Specific weakness in a range of linked cognitive function have been identified by Smith-Spark (2018) for efficiency in prospective memory function, i.e. memory for future events or action's in adults with dyslexia-SpLD. The lack of efficiency of access to verbal information in long term memory, specific weakness around perception of time and executive function differences were all considered contributory. What this did mean was that the social efficacy and perceptions of social reliability was potentially challenged unless alternative support was implemented. Although as Diamond (2009) notes in her important summary for developmental psychology of genes x environment interaction (epigenetics); cognitive development findings in adults could not be unilaterally applied to children, the findings of Smith-Spark (2018) suggest that en route to adulthood the memory systems became compromised since it was unlikely that robust systems would suddenly spontaneously fail in adulthood.

Consequently, consideration needs to be given from an ecological framing how early manifestations of difficulties in this information processing area may contribute to future

problem areas and disrupt education. Dislocated learning that leads to a lack of confidence in the ability to handle disruption and meet challenges may have wider and extended impact on individual capacity over the longer term (Livingston et al., 2018; Miles et al., 2006). The critical issues in this study were how the profile of dyslexia-SpLD in terms of cognitive processing systems differences interacted with the environment of school and home to engender additional disruption for the child and those around them. Secondly how particular events were situated as key points of change. Both these elements have potential to impede inclusion though disruption of a child's capacity to maintain parity with peers in both academic as well as social function domains.

The sub research questions for this chapter then are focused upon identification of features visible or hidden that had potential to disrupt or shape how inclusion was perceived, enacted, and experienced by children with dyslexia-SpLD and their families. The two questions were:

- What mechanisms disrupt smooth transition and full participation in positive inclusive education throughout the Arc of Education?
- How are the risks to fulfilling a child's educational promise and their access to inclusive education identified and conceptualised by parents and school staff?

How are discontinuities and disjuncture understood in this study?

This chapter considers evidence of the impact of disruptions on the developmental trajectory of children with dyslexia-SpLD. The progressive hierarchy describing disruptions and their consequences presented in this analysis represents a novel contribution to knowledge. It is recognition that while for typically developing students they will bounce back or take in the stride everyday hassles and disruptions, for the children with dyslexia-SpLD those similar events will or at least have the possibility to generate greater disruption and more pervasive consequences. The impairment they have in cognitive processing and memory function creates

risk of disability due to the interface of the cognitive function with environmental demands, consistent with the social models of disability (Macdonald, 2019). The impact reflects the findings of the negative consequences of increasing the hassles in everyday life on health (Kohn et al., 1991).

The chapter considers what happens when children are unable to engage in aspects of developmentally expected transformations and maintain peer parity. In the preceding chapter 5 (Visibility), there were multiple accounts of the impacts of lack of equivalence in the development of skills, learning, progress or access in education that also generated risk for the child, their family and indirectly to their classmates and the school. A closer examination of the nature of discontinuity and disjuncture, as it pertains to raising the risk for poor outcomes and experiences of inclusion for children with dyslexia-SpLD was therefore merited.

Case study: Kevin's' science lessons

Kevin's story is an exemplar to illustrate key features of the theme of discontinuity and disjuncture. He was in Year 8 and had a severe dyslexia-SpLD profile which had been resistant to school delivered intervention, as became apparent from assessment findings. In the two-part extract below Karen, Kevin's mother was responding to a question asking her to describe examples of inclusion occurring and not occurring. She first describes teachers and a support worker that adapted to meet Kevin's needs, and in the second extract situations where needs were not met. What was unexpected was that the two examples she chose were from the same school and science subject in sequential years. The differences occurred due to a change in staffing:

Extract A

KAREN: he has worked, he worked really well with the science teacher. So well, that I thought he was sitting next to someone to do this work. He was getting incredibly good grades and I think for that teacher, he took the time, he explained Kevin very carefully, very simply and very practically what was needed. Kevin felt able to go and speak to

him separately. He also had an incredibly good teaching assistant in that, Mr Bean, who unfortunately now, has now gone, who Kevin bonded with and felt comfortable enough to say, "I don't understand this, I can't do it".

Extract B

KAREN: *I'm just thinking what's happened Kevin now, the science teacher wasn't, didn't have him this year. He's had two years with him to be fair, so he's done well. He had a new teacher and I had a call in the first week. Kevin was mucking around and not settling down and I was really shocked because he likes science and he felt he was good at it. So, I don't think that teacher had understood, and I think had been, well, from talking to Kevin she was going too quickly. There wasn't a practical. He couldn't visualise what it was. It was lots of words and lots of things that didn't make sense. So, he needed to see it more practically and what he meant and have a better, what's the word, more explanations, and practical explanations, I think.*

Across the two extracts for the same subject/class group, the changes of personnel of teacher and the support staff worker seemingly were the critical aspect that made the difference in outcome. The point of reflection and insight for the theme was that other students in the class would have had the same change of staff, but the account offered by Karen was that he was one of a limited group who had not responded well to the change. The rest of the class had not seemingly decompensated in the way Kevin did. Kevin went from achieving well, enjoying a subject of study and producing good quality work in his mother's estimation, to his mother being called from the school to discuss his behaviour of "**mucking around**" within a week of the new academic year starting.

Making sense of Kevin's' lesson experiences: abstracting relevant information

Taking the first extract, it detailed accounts of recognisable pedagogic techniques including scaffolding of tasks (Janneke van de et al., 2015), that supported and maintained Kevin's access to education. Features that were described by Karen of the paring down of processing demands, with the use of clear simple language, multi dimension/sensory teaching and using visual clues, reflected sensitivity of need by the successful teacher. The account

supports that adaptations were made in the setting by the adults rather than Kevin adjusting his way of working.

The teaching staff provided accommodations; firstly, to language/communication used for the processing of educational material delivery, and secondly, created the capacity of trust between a pupil and staff for a vulnerable learner. Absence of the scaffolding that had been provided by the teacher and support staff resulted in rapid decompensation for Kevin which resulted in his mother being called. That abstraction pointed to what a fine line was being held in maintaining Kevin's presence in class, and how accommodation and support was sustaining Kevin in a state of good education. This example illustrates how some of the features for dyslexia-SpLD discussed in the literature review occurring at the real level (language processing, processing speed, short-term memory, and working memory, collectively characterised as individual differences) impact upon functionality in the classroom that extends beyond the individual ability to read, spell or write, but rather how to maintain pace and parity with peers in the structured moments of the rhythm of learning.

Typology

Types: Micro, Meso and Macro

Across the data there were three broadly described ascending levels of discontinuities that were qualitatively different from each other. The progression was linked to the perceived size of the impact, as described by the participant, rather than the size of the event that precipitated the disruption. The terminology in this study is independent of Bronfenbrenner's use of similar phrases (Shelton, 2019), instead they describe the type of impact a disruption had on the functionality of a child and their access to education

Micro was described from the data as short term, transitory disruptions, for example Karen disclosed **"he's forgetting his PE socks and he's not getting his diary signed"**. They were predominantly located in disruption to organisational sequences and driven from the

child's differences and difficulties with cognitive processing particularly, around memory 'to do things'.

Meso occupied a broader span of the spectrum and was a more explicit interaction between the child and the environment which cumulated in a brittle fissure. Tracy's account of Thomas, her son who was in Year 7, captures such a dissonance **"I don't know because it's just a gut feeling, he's doing letters and sound through the beat dyslexia but he's been asked to critically analyse, he's doing the boy in the striped pyjamas"**. The range for this was wide, from the minor end of disengagement as described by Yvette of Yves her son **"switching off from school work, he just didn't want to engage with it because he knew it was difficult kind of thing"** to the accounts similar of Kevin where a substantial recalibration was required as part of repair.

The final level, Macro, was explicit disjuncture in which a schism arose or was predisposed to occur and where repair in situ was not possible or likely without substantial significant changes in the placement, provision or relationships. An example was Nora describing her confrontation with Local Authority Officer about how mainstream provision had not worked for Nathen: **"She said for you to get us to pay for a special school, we would have to lose, and I said okay let's just do it. So that's when we went through the appeal."** Nora won. Each of the levels shapes the experiences and differences of inclusion for the child and the following sections examine that aspect in more detail.



Figure 22 Graphic representation illustrating relationship between three levels of disruption on the discontinuity-disjuncture continuum

Micro discontinuities and their contribution to disturbances of inclusion

Micro discontinuities are akin to everyday hassles. Although minor they disrupt the smooth access to learning and disrupt the child's engagement as described in the following extract:

KAREN: "he's forgetting his PE socks and he's not getting his diary signed" and, as far as I'm concerned it is really minor stuff. Now I know they have to clock all of this and I tried to explain to her that he, sometimes does have difficulties with his personal management and she just cut me off, "he needs to take responsibility. He's Year Eight."

What marked micro events out from the typical was both the prevalence and the persistence of them. There is a sense in Karen's account how the world remained a surprise for Kevin and with a pattern of being an unexpected place (and not in a good way) for him. The broader impact and tolerance of those forms of micro disruption were variable, illustrated by the differing responses of mother and teacher. The form tutor's response was both a marker for expectations of typical development (ability to be organised and hold in future memory actions to be taken), but also demonstrated a lack of empathetic awareness of the wider profile of dyslexia-SpLD. The focus for the teacher was on the functional reality of disruption to efficient organisation and delivery of educational activity.

There was no sense of awareness even indirectly about how the well documented wider linked difficulties often associated with dyslexia-SpLD, such as processing speed, working or short-term memory differences, and difficulties with organisational function, could present in the real world in the reported teacher's account. By contrast Karen without technical knowledge had intuitive understanding of need. The implications for children like Kevin were that they publicly fail on a regular basis, and that cumulatively such failure has negative consequences.

The relative difference between parents and teacher in prioritising the micro disruptions, points to relative differences for understanding the impact of those disruptions. For the teacher working at the group level the child's actions/non-action/compliance potentially disrupt the group flow, rhythm of work and capacity to deliver on demands. For the parent dealing with significant learning issues and potential home distress for a child, they remained minor.

The extract was an example of the emotional reaction and incipient hostility in adults generated towards/around a child with a difference in processing, operating in a typical development setting. The micro disruptions and difficulty learning then had from the extract above cumulative impact and had through further events potential to create disruption in relationships needed for successful outcomes. In some cases that hostility became explicit as Karen described above, and also retold by Beth who had been describing her son's cumulative difficulties with literacy and accessing education in general. Beth described in reporting back a conversation with reception teacher **"well, I think there is because he's not picking up what you're trying to do"**.

By Year 2:

BETH: That he was lazy.

I: So that was their explanation?

BETH: He was lazy. I said: 'he's not lazy, he has a difficulty'. 'No, no I think you'll find Bob's just lazy'.

Bob was 6 years old.

Beth's account of the emotional reactions of parent and teacher and their different explanatory frameworks also highlights that the ramifications, of features like micro disruptions, were that they potentially generate over time a cumulative wider negative impact on those around the child and the conceptualisation of the child. By implications that has the

potential to be reflected back and absorbed into the child's self-narrative, it was salient to notice how many parental account the child referenced themselves as stupid or variation of that term, as Xara demonstrated in the previous chapter ("dummies' group") and found across the literature (Livingston et al., 2018).

The visibility of micro discontinuities

In the following extract Hannah, a SENCO in an urban high school, had observed the impact of micro discontinuities for pupils when she described the impact of working memory difficulties within a class. However, it was notable that each of the features she mentioned act to disturb the flow of learning, with a realistic impact of increasing the level of fatigue and challenge for the pupil while in the process of repairing situations or managing the demands.

HANNAH: *With dyslexia, my understanding is that obviously the most obvious is the impact it has on the literacy, obviously the writing, the processing of information, and then on a wider level, organising thoughts in writing, organising generally with equipment around the school, organising awareness of time and being in places at certain times and remembering to do that. Obviously working with memory and how that impacts on certain lessons*

It was unsurprising that the presence of the micro discontinuities had greater transparency in high school, where a child's typical development trajectory would suggest progressive independence and less consistent oversight and support across the school day, in short less access to scaffolding. Indeed, it is possible to infer that progressive independence was an important part of the transitions to social independence and inclusion post education. The other differences between levels of education were that in primary school characteristically the children had one teacher throughout the day/year who had a depth of knowledge about the class members. That was not the case in high school where a pupil would be faced with a series of teachers across the day, with varying levels of insight to their lives and experience. Deviations from the expected independence, would therefore come to attention.

That was exemplified by Karen's extract discussed previously. However, as Beth's account alludes to, the origins of the difficulty lie back in primary education.

The role of cognitive processing: poor attention and memory and links to discontinuity

The causal mechanism for disruption is most explicit at the micro level; there is a short visible chain between differences in processing, difficulty encountered, emotional impact, and disruption of educational access & associated inclusion. However, they on a unit-by-unit basis do not lead to major discontinuity, it is the cumulative nature that gives rise to the problems described. For example, Kevin's teacher was given an impression of unreliability and additional work for the surrounding staff, who may also be operating under pressure as was described by Hara **"So, we have a two-week timetable, we have 50 lessons and I only get five [prep], so I teach 45 lessons"**. Parents put in extra time, effort and accommodation to navigate demands for their child, but across the data only limited action was observed from the school main and sub cases to seek to change the pattern of transactions with the environment the child has, and that tended to be on an individual teacher basis.

Although for most parent participants the detail of their child's cognitive profile could only be inferred from the narrative, for some, more quantitative evidence was available. In the following extract Ann commented on the insight provided by cognitive assessments for Andrew who was in Year 7 at the time of the interview. The assessments were initially for identifying needs linked to dyslexia-SpLD but also highlighted the difficulties of working memory for Andrew. Consequently, changes were put in place based on this information:

ANN: because when I introduced the issues of memory and organisation, I basically completely changed how I dealt with my family as a result. That took a huge amount of stress out. I found other ways to do things. I didn't expect certain things to be done a certain way, and as a parent I completely changed my priorities.

Ann's account illustrates how assessment information, if accessible, has wider uses. For Ann it was the recognition that children with the dyslexia-SpLD profile typically, and Andrew specifically, had poor memory and organisational skills consistent with Snowling et al. (2020). Ann understood it as part of a common pattern for the community of people with learning differences, not as an abstract, but as a real thing. The recognition of why Andrew sustained regular hassles from incomplete tasks, misplaced objects or forgetting information, creating multiple micro discontinuities in education and home life was helpful to her. In common with Karen's account of Kevin, how Andrew operated also caused difficulties and additional work for those around him. The information from privately commissioned assessments allowed Ann to reconfigure expectations and ways of working as a parent, reducing the wider impact on the children and family. In that extract Ann described a process of mitigating effects by changing her way of working and consequentially reducing the opportunities for micro discontinuities. This information, once it became visible, was easy to use but the lack of visibility meant the causal agents for ongoing difficulties were not apparent until the assessment findings disclosed it. However only a few of the parents interviewed had access to such information, (mainly the ones who had needed to launch an appeal/engage in the tribunal process) and fewer demonstrated full understanding of it when the discussion with myself turned to assessments.

In the example below Oliver has correctly pushed for an assessment for his son Owen, but he has not understood that such an assessment and recommendations have no legal weight. The recommendations were optional for the school to implement. Indeed, it was legally as if the assessment had not taken place. A Statement of Special Education Needs was required to put a legal obligation on the school and Local Authority to provide extra support, something most parents did not know. All this confusion and misreading of the legal position and the role of assessments was common throughout the parental data.

OLIVER: *[...] So we got that done and a statement done, went into secondary school.*

I: *So he actually got a statement.*

OLIVER: *Yeah you get a report back don't you, not a statement sorry, a report back with recommendations in there. He had, I can't think what you called it, the learning plan Owen had that learning plan.*

Challenge self-competency

Oliver also noted his children Owen and Oscar could also seek to self-manage the risk of micro discontinuities and overcompensate to control social and personal stress, but that also carried consequences too:

OLIVER: *whatever it is because he's particularly like me, he's very anal, he's very protractive in the things he does, it has to be precise but saying that, in the real world, that can work very strongly for you but it's given in him, in Oscar in particular, Owen is a very social character, Oscar has almost because he's being so anal, it's giving him friendship barriers and he's, if things aren't quite perfect [...] So there's definitely intelligence within these children and dyslexic but they are put down and they underachieve because the system isn't there for them.*

A strategy of overcompensation, which may enable a child to maintain the appearance of parity with peers and of getting it right also had costs, which according to Oliver created an additional burden for the child. What Oliver highlights also is how two children with differing ways of 'being in the world' navigated the same type of educational space. However, for Oscar his strategy had another potential impact as well, it meant a lack of visibility to teachers of his difficulties. He used alternative means to achieve a goal and had it seems low visibility, therefore teaching staff were not recognising the challenges he was facing and possibly not supported effectively, an aspect referenced by the comment of "*underachieve*" by Oliver. This draws from similar accounts in chapter 5 (Visibility). In the literature review, comparable observed phenomena were referenced as bootstrapping (Muter & Snowling, 2009), which also

implicitly suggests extra effort was required and that it was a work around, something Oliver alludes too. One of the features of dyslexia-SpLD mentioned in the literature review was its invisibility (Barbiero et al., 2019) , variable presentation (Carroll et al., 2016), and the variable ages it was identified/formally recognised as demonstrated in the school census identification of SEND (Gov.UK, 2020a) as outlined in the literature review.

The evidence considered so far in this chapter suggests how individual children's characteristics and the circumstances they find themselves in moderate outward visibility to the school. However, parents may have important insights, about the child's internal world, the physical and cognitive demands and social experience.

There were examples in the data of how risk of collateral social damage was mitigated. Family, adaptations, and accommodations applied to minimise the prevalence of occasions of difficulty. For example, Lucy on Larry (age 14) **"if you can check not every night but every other night that your pencil case is fully loaded with everything you need for the next day you're ready to go mate. Without me saying that it never gets done"**. Lucy had through that monitoring engaged in a form of supportive inclusion as she had sought to minimise the impact of those micro disruptions and associated teacher responses by supporting Larry and checking on him.

Nevertheless Holly, an experienced high school teacher, noted this support was not always the case: **"There again if I try and think of my dyslexic students, they are often the ones who are missing something."** Alternatively, the problems may not have been recognised or acknowledged by parents due to normalisation, because such disruptions were part of their own lived experience, as Oliver noted above.

This type of micro disruption and its contribution has not been given the depth of evaluation in the dyslexia-SpLD literature and represents a new area of inquiry. One that from the data suggests plays a role of significance in how access to education is maintained,

progress made, parity with peers secured and the way inclusion is shaped by the presentation of a lack of competence over time. The core issue for this form of discontinuity was that there was a transparent mechanism that linked lack of efficiencies in fundamental processing at the child level, that built on and shaped subsequent processing and functional limitations in the educational environment and impacted upon self-perception.

Meso discontinuities

In contrast to the linearity of the micro disruptions, those occurring at the Meso level emerged from a confluence of factors, typically emerging as a mismatch between the dynamic environmental demands and the capacity of the individual to meet demands from within the resources and skills they had. It was at this level complex skills such as reading, spelling, and writing became observable barriers and marked out differences with peers at both the skill level in literacy development, and also contingent knowledge acquisition. In combination they suggested a trajectory. At this level there was a progressive set of contributions over time, to what became a point of fracture. However, there were two ways of conceptualising the discontinuity at this level, one where it increased the difference and difficulty, and another where it provides a reset opportunity to change the trajectory pattern. Both can be seen in the data and it is useful to start with account of positive discontinuity.

Positive disruption, discontinuity, and disjuncture

The data revealed not all discontinuities and disjuncture were negative, sometimes they resulted in positive shifts and opportunities that had benefit as an outcome. As previously discussed, Yvette had experienced real difficulties with her son Yves's school in gaining the visibility of a diagnosis for him: **"and they literally said what do you hope to achieve by having a label"**. In this case an exemplar of meso discontinuity with a positive outcome came in the form of a temporary teacher who joined the school:

YVETTE: *We were really lucky actually. When he went into Year 3 his class teacher, well I say this was lucky, it wasn't for her, she was off with a broken arm for a while and so he had a supply teacher who was amazing, and he said at a parents' evening I strongly believe that he's got dyslexia, and this was before I'd said anything to him, he'd just identified it, and he pushed for more support in the school. [...] But then the other thing that the supply teacher did was say don't just concentrate your efforts within school, reach out and see what else is available to you and, because of that, we found the Dyslexia Association.*

That introduction of an outside agent changed the direction of learning travel for Yves. For Yvette it modified her confidence to pursue diagnosis and put her on track to secure extra support for him. In this case it was the introduction of an external other that disrupted the pattern. The overlap between the events and change of trajectory links closely to participant's experience of their own agency, a theme explored later on in chapter 7 (Agency). However, with respect to this theme, disjuncture provided a situation in which system inertia could be disrupted.

The problem of non-disruption of trajectory

The importance of disruption can also be exemplified in a more negative sense, i.e., when it does not happen. In the following extract there was a key opportunity upon transfer into secondary school to change Thomas's trajectory, but the school hid the results from a screening assessment from the mother and then took what could be reasonably concluded to be ineffective action.

TRACY: *He's had a dyslexia screen, but all of them get a dyslexia screen but we knew he was dyslexic.*

I: *And what did come out?*

TRACY: *Well I never got the results shared but she sort of said 'well everybody gets screened at that' and as far as I can tell, he's just got, he's being pulled out of citizenship classes and he's done paired reading for a term which has now stopped and now he's doing handwriting but to my knowledge, and he's in bottom set for everything, to my knowledge that's all the help he gets.*

Thomas's mother described the impact of this **"I'm so embittered by the entire education system that I don't, my expectations have just gone through the floor"**. Thomas's history and levels of literacy skills as described were commensurate with a Year 1 child when he was a Year 7 pupil. That level of discrepancy, if supported by professional documentation such as school tests, would qualify for the statutory form of assessment called a Needs Assessment (Department for Education, 2015; Wolfe & Glenister, 2020). However, it did not appear from this account that anything of substance additional to or different from ordinary provision was being applied. The trajectory of progressive failure was not being changed.

A failure to make progress was a recurring theme as Wendy, mother of an 8-year-old noted, **"His assessment said he had made no progress in eight months."** So, an important aspect of meso discontinuities was that despite examples of poor fit between the child and the school, causing tension and fracture, opportunities were missed to overcome system inertia and consider the longer-term implications to independence and inclusion. The data in this case did not support that the system could self-correct following a state of discontinuity.

Operating close to the edge of failure - discontinuity and risk

Across the data the different types and levels of discontinuities generally added to the burden of educational access and inclusion at the child level. Here substructure of discontinuities is considered, specifically the cumulative impact of sequential ones; over a period of time, Dave's learning support assistants were not available for lessons to provide additional scribing and scaffolding for him.

DIANE: ***The help just wasn't there, because they literally didn't have anybody.***

I: ***But what happened to him as a result?***

DIANE: ***He became very angry because he found himself struggling, but it took him a couple of weeks of this happening to actually***

come and tell me that this was going on. So then obviously I was back onto it...

The example demonstrated how a source of disruption (lack of available staff) became a progressive and serious issue for Dave relatively quickly, but seemingly was ignored by the school until formal attention was drawn to the matter by Diane. Across the interview Diane gave an account at the start of each year having to go through similar process as attempts were made to ensure the provision was made **“obviously I’ve had the same issue each year”**. While ostensibly the problem was a lack of staff, and the initial explanation was that the gap in support created the discontinuity; the critical question was how inclusion was being formulated by the school, Dave and Diane. Dave was being partially accommodated, but was not independent, his presence in the class was fragile, in a similar way to Kevin’s. Based on the accounts, both Dave and Kevin were operating at the maximum capacity, they had no further headroom to address the additional situation demands. This was an account of virtual inclusion; one contingent upon the presence of another to enable accommodation in the setting. However, it was also an account of tipping point, a rapid splintering linked to the sustained lack of skill and capacity development. Causally it was not something suddenly occurring, it was cumulative over time that hit a critical point when the elastic limit of compensation failed.

Both cases illustrated that the fragility was also linked to emotional health. The impact then went beyond access to a specific piece of knowledge or learning and into psychological distress expressed through behaviours. Both Kevin and Dave’s’ responses provide additional support for the tipping point analysis. In the most extreme form of this it led to significant behaviour difficulties as Lucy described:

LUCY: And the first thing I heard about it was when he had been there possibly four or five months and he picked up a chair and threw it across the room, then I got called in because obviously that’s bad

behaviour, and I went oh right, okay then, I said how's he getting on with his mentor, what mentor?

I: The one you said that you were putting in place, yeah.

LUCY: So then I said to her "so do all of his teachers know that he's dyslexic?" "He's not dyslexic". "Okay".

I: So why were they saying he wasn't dyslexic?

LUCY: Nothing had been written on his report, nothing, not anything. It was basically I gave them a manual from the other people, the other school, of how to help him with his learning, so it was really simple stuff, it was if there's something on the board can he have it on a worksheet, and can the worksheet be coloured, it is really simple stuff like that to help him. There was nothing. If you typed his name into his student profile it just came up with a little picture of him, it didn't have anything, nothing.

Lucy's account was the most significant in terms of violent response behaviours, but it illustrated how the lack of communication bridging the geographies of inclusion between home and school as described in chapter 4 (Arc of Education), and failure in transfer documentation processes and distribution of knowledge created toxic circumstances for Larry, who like Kevin, whose account opened the chapter, became brittle and snapped. The data in the parent case suggested there was the associated pathway between difficulties created for a child because of the situational demands with their skills, and the emotional and psychological impact creating further risk and damage. This reflects the well documented accounts in the literature for instance by Ingesson (2007); Riddick (2010) and more recently Leitão et al. (2017), as well as the systematic literature review of Livingston et al. (2018) discussed in the literature review. At this meso level, this is commonly identified by parents as 'dyslexia', and what from the data dyslexia-SpLD means to them, a situation where there is marked disruption between skills and situational demands and risk of collateral damage.

Creating visible discontinuity, the problem of intervention

So far, the accounts used to illustrate have been from teenage boys. However, other evidence from the data such as Xavier's account about his daughter Xara which was mentioned in chapter 5 (Visibility), is instructive of how early damage resulting from poor match of skills development and demands lays foundations for what followed in the descriptions by parents above. In Xara's it was the formal identification of difference and difficulty though group allocation that was leading to the longer-term hidden damage:

XAVIER: *My daughter is much more self-aware, she's a girl and she's clearly aware that 'she goes to the group of the dummies', as she says 'she's dumb', and she takes it psychologically and emotionally. It's much harder for her.*

I: *And how old is she?*

XAVIER: *She is 7 next in two months.*

I: *So she's already got a view of herself as being a dummy at the age of 6/7?*

XAVIER: *Yeah.*

I: *That's really sad.*

XAVIER: *Correct, I wish she would get some support*

Xavier's account was useful in the study for it was a clear representation using his child's voice and language to describe the psychological and social consequences of dyslexia-SpLD in terms of perceptions of inclusion in a "group of the dummies". While all the parents' accounts described difficulties in primary education, presumably due to the mismatch of the children's skills versus the educational demands placed on them, this account shows how forms of intervention were also sources of distress. The mechanism of discontinuity had moved from the individual to the system, and the event consequences of 'othering' by the peer group (who were also 6/7 years old). Taken with Beth's account of Bob, there are important indicators in the data of how the damage caused by dyslexia-SpLD is significant and at an early age.

Across all the parent interviews there were multiple accounts of distress by their children, linked to this mismatch of skills and demands plus development and learning out of phase, multiple accounts of rapid decompensation and situational failure. An example that captures a common experience was Penny, who like many of the parent participants they themselves had dyslexia-SpLD and relived their child's experiences through their own memory:

He gets terribly frustrated because he's very intelligent and it's this wall of frustration. The thing is, I can feel it myself because I used to get it at school.

I: Yeah, yeah join the gang.

PENNY: This frustration that he wants to be able to do it but he can't or he can't put down in writing what it is he wants to say.

In contrast relatively little was noted in the school case study data. It was the absence of comment from the school case study about the mental health aspects that was striking, further while the literature considered the mental health aspects of older children/young people (Carroll & Iles, 2006) it did not seem to have widely examined them for younger children. Further, what comment there was from the school staff was unevenly distributed. Teachers who themselves had struggled or had insight through knowing somebody close did convey empathy to pupils, for example Frank's verbal support to his struggling pupils **"just geeing them up and saying you can do it, keep going"**, but he then went on to say **"I was never diagnosed but I was in the special group for literacy"**. The aspect of distress linked to the profile of difficulties in literacy was seemingly not registering in the school study broadly. Instead, teacher participants noticed more general behaviours, for example linked with poor organisation as mentioned by Hannah. There were limited observations on ability to read write or spell or complete work set in line with peers, or to consider the longer-term impact of those difficulties on firstly, progress through the Arc of Education, and secondly, wider social post-school life.

The meso level of discontinuity reflected the long-standing accounts of the costs of dyslexia-SpLD to children and their families (Bull, 2003; Burden, 2008; Griffiths et al., 2004; Riddick, 2010). The accounts in this study have not shown much if any change in substance from the historical ones or even the more recent ones (Leitão et al., 2017) despite advances in technology and teaching strategies (Griffiths et al., 2013). What has been considered here is both the mechanism of the disruption and the tipping point when matters come to a head and their ramifications. The parental accounts taken overall provide indicators of the long-term damage caused by the cognitive profile of features that lead to and shape dyslexia-SpLD in the form of disruption to learning, inclusion and attainment. That damage, as captured in the extracts so far, extends beyond the difficulties in reading and writing. The parents also provide accounts of how that negative trajectory could be modified and that is considered in the next chapter, dealing with different aspects of parental, child, school staff and others agency. The key matter with meso level difficulties was the cumulative nature of the contributing causal features over time and the degree to which the visible tipping point events suggested how under pressure the children and young people in the setting were. In the final part of the spectrum the level of poor fit results in rupture.

Macro level: educational failure and opportunity

Introduction

Macro disruptions were identified by sharp ruptures in continuity of progress, attainment, access, or development for the child. In abrupt disjuncture cases, the impact was significant. The level of risk increased at structural transition points, notably primary to secondary education where the education system characteristically has sharp departures of practice, as described in chapter 4 (Arc of Education). Extreme disjuncture was characterised by a breach in educational access and inclusion which had cliff edge qualities and marked ramifications for the child, family, and school. The consequences for inclusion and the child's

sense of self within a community were significant. For some it provided a chance of new start, for others, the effective end of their education.

In the data disjuncture occurred in one of three ways, which will be discussed in turn using examples illustrated by extracts from Yvette, Frank and Wendy. First, when there had been sustained distress for the child arising as a product of, or in conjunction with, persistent unresolved difficulties around access to education or inclusion; Yvette's account is an illustration of that. Second, a rapid service failure when there was a sharp displacement between the skills that were expected to be in place for that child/peer group, and the skills and capacity the child had; Frank's account is an illustration of that. Third, when there was cumulative failure to make progress and sustained difficulty gaining full access to education and/or only partial inclusion; Wendy's account addresses that aspect.

Positive outcomes from disjuncture

An example of positive opportunity was Yvette's experiences, who moved her son Yves from one school to another as the original school had not been able to ensure educational access and inclusion over a protracted period.

YVETTE: We decided, because he was so unhappy, we decided to move him for Year 6, and we were lucky [redacted], so he moved to School B, and massively improved, the support that he got there and the friendship groups.

Yvette's extract captured that the ultimate disjuncture of leaving a school may be an effective solution to ongoing and unresolved discontinuities of access and inclusion, with no foreseeable change. Yvette had provided an account of a child who was significantly above average intelligence when she mentioned that the educational psychologist said "**she had done these puzzles and he was really good at doing those**" and the psychologist also talked about the disparity in language, however for Karen it was the more nuanced real world evidence that counted "**so he'll listen to the BBC World Service when he's going to bed at**

night” (he was 11 at time of interview). He had sustained difficulties with dyslexia-SpLD, no additional support from school, and parents paying for additional outside school specialist lessons. The distress Yves experienced also caused family ructions particularly around homework **“I have to admit that before that point I used to get really quite frustrated with him, like doing homework”**. Moving school became a positive experience. Yvette describes a situation where Yves moved from a setting with poor inclusion, to one of inclusion, and associated benefits.

Negative outcomes from disjuncture

A second form was rapid service failure, albeit that the causal features may have been embedded earlier in the span of education. In the following extract Frank, a teacher of 20 years working in a socially deprived catchment area, reflected upon past groups of vulnerable children in the school, who included those with literacy difficulties:

FRANK: *We find that a lot of the children that we’ve spent 7 or 8 years with, they go to secondary school and that is the end of their education.*

I: *How tragic, how absolutely tragic.*

FRANK: *We have a lot of children that we’ve said, you’ve got through, we’ve kept you going and then they are expelled or excluded within about two or three weeks. But we have some success stories, like I say.*

I: *So if you look at the kids who’ve got the literacy difficulties, are they the ones that end up getting expelled?*

FRANK: *It’s more behavioural with those children, but again sometimes that’s linked. So I mean, we’ve tried to keep children here as long as possible*

Frank’s account confirmed that significant discontinuity between phases of education had high consequences for at-risk children; including those who had literacy difficulties as part of their profile. In Frank’s account **“you’ve got through, we’ve kept you going”** captured another version of other voices in interviews, by use of his teacher voice to speak to children.

Teacher accounts suggested they were dealing with sequences of discontinuities and potential disjuncture's **"we've kept you going"**. The extract suggested the way in which primary education, and primary teaching staff, are extending themselves to try and maintain children in education as a fundamental form of inclusion, that of having a presence in the class (Göransson & Nilholm, 2014) particularly in this case for vulnerable children. Nevertheless, the breach of social and academic function and the security of learned skill sets required for high school educational access between the two institutions had not been established. The deficit could not be resolved by the child. At the end it cost the child their access to education and capacity to change their life chances for the good. Those were the kinds of outcomes that Deacon et al. (2020) explored in their biographical based study and how damaging such childhood experiences was to longer term self and wellness and which Hutchinson (2021) using English national meta data identified in her analysis of the identification of SEND.

Creating the circumstances of disjuncture

The third form of disjuncture is located in the cumulative impact of progressive damage over time. This was reflected in the degree to which parents had moved their children's school or actively considered such a move. That was evidence of significant disjuncture or risk of rupture within a child's educational provision. The point is made by Wendy at the end of a long discussion about the difficulties she had encountered with getting support for her son from his school.

I: So in terms of thinking about this schooling system that Wayne has to get through because he is eight now isn't he, and in primary school, have you at any point thought about actually if this school isn't working, is it worth going to another one?

WENDY: **Yes, lots of times.**

I: So why have you stayed where you're at?

WENDY: **Because I'm worried about the other effect of moving him. He's not great at going to after school clubs and things like that and I just worry that the stress of that might be too much, whereas**

he is really confident with his little peer group, he likes to joke, so I think his confidence is higher where he is.

I: *So how much academic progress is he making?*

WENDY: *His assessment said he had made no progress in eight months.*

Further down the line of Wayne's educational journey, that lack of literacy skill and academic progress would realistically raise the risk of significant educational disjuncture if no additional action on top of current provision occurred. Wayne was perceived to be happy in the setting and so the situation was left as was. Risk was only partially understood by Wendy; progress had not been made but the implications were not fully appreciated. A lack of progress after eight months is a long time in an academic year to go unnoticed, and that eight months is difficult to make up. However, there was no indication in the account that the recognition of this had led to extra support for remediation.

The needs of the here and now with respect to a child being happy and confident with social inclusion had been privileged by the parent. Nevertheless, the fact that Wendy had considered a move, meant that precursors of awareness of difficulty had been activated. In all the cases where rupture did occur there was, from the parents' side, a progressive history of increasing concern that reached a tipping point. Wendy's account captured that early phase. Griffiths et al. (2004) also identified in her action orientated field study of 6 families how a system of escalating strategies of contact with school were used indicative of a progressive form of problem areas.

Across the six family cases of children who secured Statements of Special Educational Needs in this study, all parents attempted to move their child to a different mainstream school (outside the standard change of phase), at least once; two more than once, and all but one succeeded. For the latter, no local school would accept the child into Year 6 and they transferred to a specialist school for Year 7. But there were also three parents of children

without SoSEN or EHCP that also moved their child's school placement out of phase, and two of the eight parents in the small groups (one of whom was Wendy) contemplated moving school. That level of movement, actual or contemplated was something of a surprise and pointed to a more significant problem around educational access and inclusion than a surface examination may suggest.

There was no evidence in the peer reviewed literature about school moves for children with dyslexia-SpLD or literacy difficulties, but the level of movement in what was a snowball sample was unexpectedly high. Hutchinson (2021) notes in her meta data study that school moves were linked to lower identification of SEN, and suggested this maybe because of the length of time it takes to go through the process, however an alternative or additional analysis from this data was that some school are less disabling or more supportive for pupils. It was also indicative of a dislocation of inclusion. Moves could include significant distance, moving to a new house, and made primarily for educational reasons.

The data pointed to an under acknowledged mechanism by which parents sought to manage child distress and failure to make progress. This indicates the degree to which disjuncture at the macro level was a relatively unrecognised phenomenon but should now be viewed as a pertinent indicator of educational failure both for inclusion and for academic access for children with dyslexia-SpLD.

However, with respect to disjuncture what was also found was that the change of school was seen in the data to have benefitted the child, though for two participants that benefit was constrained after at least a year. In the data elective disjuncture did provide new opportunity and fresh starts for the child, and the perception of support post move was considered positively. This is a counter-account to claims in the literature about lack of benefit or damage for such moves. For two cases, work was done by parents to secure assessments so that improved support was available at a new school at the ordinary Year 6-7 transfer.

With respect to non-elective disjuncture, notably at Year 6-7 there was a mixed picture. For some such as Oliver who had secured some form of local authority assessment prior to transfer the transition had been at least partially effective, (though as will be discussed in chapter 8 (Illusion of inclusion) he was contributing £500 per month extra support for his two children). In other cases, where assessment processes had not been effective and additional resources were limited, for example Tracy or in Frank's account previously, or Lucy below, the transfer marked a downward trajectory.

The role of diagnosis and communication in disjuncture

The transition between primary and secondary school was a particular point of rupture. In the extract used in section on non-disruption of trajectory, Lucy describes in that extended extract a significant event (chair throwing) and then her efforts to untangle what had happened; in the extract I asked to clarifying question why did they say he did not have dyslexia-SpLD in relation to the information provided early in the interview and she described how they had just ignored all her information.

In Lucy's case Larry did not have a SoSEN/EHCP, despite multi-agency involvement, they reportedly could not agree on a diagnosis **"it took a year and a half to go through absolutely everything, do all these tests, and it came back inconclusive"**. This was in spite of the formal diagnosis of dyslexia-SpLD Lucy then went onto secure and the evident difficulties in accessing education. Lucy had her own views on why this was the case **"I do think, I genuinely think it was all to do with money. They've got too many kids that year that have been diagnosed with dyslexia"**.

In Larry's case an analysis of the interview identified contributing sources to the explosive disjuncture, which were many and for ease of reading they are bullet pointed:

- A failure by professionals to appreciate that a diagnosis was not essential in securing statutory support for Larry and waiting for a diagnosis as a precursor to intervention

was legally inappropriate (Department for Education, 2015; Wolfe & Glenister, 2020).

This diagnosis delay and inertia initiating intervention was also found in the school survey, so it was not specific to Larry.

- Rejection by the school of salient and relevant information regarding Larry's dyslexia-SpLD **"I'd taken it private, at that point in time the school wouldn't accept it"** again contra to the code of practice where all sources of information have to be considered (Department for Education, 2015).
- Failure between institutions to ensure smooth transition between phases of education as in the extract above.
- Failure of the receiving institution to respond to relevant information **"basically I gave them a manual from the other people [...] his student profile it just came up with a little picture of him"**.
- Failure to use class-based information which should have been apparent to put in appropriate support and adjustments as above.
- Failure for Larry to be able to engage with education and a critical examination of why **"he picked up a chair and threw it across the room"**.
- Accounts of poor-quality relationships between teachers and Larry.
- Failure of communication between home and school **"the first thing I heard about it was when he had been there possibly four or five months"**.

Larry had a long history of dyslexia-SpLD problems and coexisting profiles including hyperactivity from early years/ primary school and this was according to a study by Carroll et al. (2005) not an unexpected co-occurrence. Yet despite multiple professional involvement it appeared no effective plan of action was put in place despite this kind of severe behavioural profile linked to dyslexia-SpLD having been examined in the literature (Dahle et al., 2011). In effect he and Lucy were observed and documented but not engaged, and when Lucy secured relevant information, they were ignored, for example when Lucy secured a private assessment

of Larry **“Oh yeah, he [assessor] wrote a massive report but, because I’d taken it private, at that point in time the school wouldn’t accept it because they hadn’t done it.”**

The failure to use relevant information included both schools not effectively working together to ensure an accurate and effective transition plan was in place. Instead, it was left to his mother to sort out and in this respect Larry’s account echoes the one for Frank and his pupils earlier in the chapter. The transfer of information between primary and secondary school is a well-recognised point of risk for children with SEND (McCoy et al., 2020). Risk reduction is effected through planning and distribution of specific knowledge to staff, and in communication between school and family (McCoy et al., 2020). In Lucy’s case there is no evidence that this process was completed. The outburst and the rupture of education was the accumulation of multiple system failures. In this case Larry was paying the price of failures by those tasked professionally to meet his needs, but the price was being paid long after their actions or inactions.

A number of those, such as refusal to accept reports or diagnosis of outside agencies, were a pattern in the data and will be considered in greater depth in chapter 8 (Illusion of inclusion). However, as the rural primary school in chapter 5 (Visibility) illustrated, there are other settings that did embrace parent contributions and information and maintained a critical stance on their own practice. What the data across both case studies point to, is that there was variability in the individual school settings to accommodate different forms of evidence of need and responding to it.

Change of schools represents an absolute failure of inclusion for a particular setting, which notionally had a mandate to meet that child’s needs. From the parent case study, it was highlighted that mainstream education was something of an archipelago, an island chain of provision in that each institution had variable features. Each of the islands of education were doing their own thing, within the broader context of a common eco system. However, over

time that had led each school's character and provision to be unique, and there was not necessarily a good match between how a school situated itself and the child at that point in time. This formed a demi-regularity in the data.

There were clearly schools that did not meet need and ones that did for the same child, illuminating the variability and happenchance nature of education for the children referenced in the study. The disjuncture linked across the data of accounts of children with dyslexia-SpLD operating much closer to the edge of failure, being brittle under duress, where relatively small changes in educational access support had significant ramifications. At the macro level the mechanisms of educational risk had become complex, anchored outside the immediate context, the events however have wide ranging impact.

Bullying as a form of macro disjuncture

An area of disjuncture not directly addressed in the sections above was bullying. It was relatively hidden from adults as a phenomenon (Glazzard, 2010; Livingston et al., 2018) and so school staff participants did not raise it. Consequently, it did not feature in the school case study or was minimised -for example Frank **"No there are so many children that are in the same grouping, they don't pick on each other for that sort of behaviour"** which may have been a true reflection, but he did note **"They'll say things about each other's mothers"**. In contrast it was however apparent in the parent case study as a serious macro disjuncture at the child level, and an absolute breach of inclusion as an experience of respect and equitability. Xara referenced it when referring to herself as part of the **"dummies"** group, and Tracy who captured the common account succinctly **"because he fell behind everybody else, he then started to be teased, it then affected his self-esteem. He then got bullied and he just absolutely hated school"**. Every parent except one gave an account of bullying or child humiliation for their child linked to literacy, or their child putting themselves at disadvantage to avoid bullying as Penny recounted:

PENNY: *He doesn't want to be seen as different to anybody else so he fights against that. He was given the opportunity to use a computer in class to put down his work because it's easier than handwriting, and he turned around and point blankly refused.*

The poor visibility of the child-level macro disjuncture of social relationships linked to functional differences is a significant area of impact. The difficulty for children was they may have **had** rupture in relationships, but they were required to be in proximity to peers involved through school attendance. The relevance of the bullying is again poorly represented in the literature, and in which some academics in commenting upon dyslexia-SpLD have in their account either minimised or belittled (Gibbs & Elliott, 2020; Lauchlan & Boyle, 2020) and occasionally been challenged back from such belittling accounts (see Brown, 2020).

Implications for inclusion

The sub research questions that headed this chapter focused upon the mechanism that had potential to disrupt or shape how inclusion was perceived, enacted, and experienced for children with dyslexia-SpLD and their families. The two questions were:

- What mechanisms disrupt smooth transition and full participation in positive inclusive education throughout the Arc of Education for children who have a dyslexia-SpLD profile?
- How are the risks to fulfilling a child's educational promise and their access to inclusive education identified and conceptualised by parents and school staff?

In terms of sub-question 1, this chapter demonstrated how children with dyslexia-SpLD experience more difficulties with ordinary or typical disruptions in everyday life, learning and peer relationships. The mechanisms involved, as reflected by the three levels of disruption that form the discontinuity-disjuncture spectrum, are central to both how dyslexia-SpLD and inclusion are experienced by the child, the parents, and the school staff. The persistent feature throughout is one of distress. That profile of psychological stress and distress has been a

persistent part of the accounts of dyslexia-SpLD and being perceived and contingent upon the specific limitations of reading-writing and spelling. There was so much material generated in this study under this heading that it had the potential to form its own study.

What the quantity and quality of the material did allow was an account that described the mechanisms of disruption and the event impact. The data illustrated how the damage to a child's sense of inclusion was evident at age 6, and that micro discontinuities contributed into challenges and stressors of a child being in education, making progress and accessing learning, but also the challenges were for family and school staff.

The meso level described the mismatch between the child's capacity and the situational demands. That level described what parents and others commonly described as dyslexia-SpLD. At that level repair was potentially available but patterns of dislocation with the peer group and family were being established, exacerbating risk to educational access and inclusion over the longer term. The data demonstrated the complexity of factors that can contribute to or mitigate against risk.

The final level, macro, was the result of either structural failures in the segmentation of phases of education or due to the very poor level of fit. Principally this was between the child's capacity to sustain daily functionality and the level of flexibility in the setting to adapt to accommodate or remediate difficulties. But it also described a hidden rupture, that of bullying and outsider status which the child could not resolve. Repair in such cases required radical change of provision, setting or both, with active agency by both parents and school, an issue dealt within the next chapter.

With regard to sub-question 2, the chapter has illustrated that either side of the meso level there were other forms of discontinuity that had impact on how inclusion was experienced. However, while the accounts contained observations of different forms of disruption it was not the case that parents or teachers identified these as linked or why.

However, the parents' accounts in general focused upon their individual children did provide greater granular detail and potentially better access to identification of risk.

While the broader meaning and parental understanding of dyslexia-SpLD is at the meso level, the evidence points to the salience of the micro level as functionally important. And the macro level for both explicit and hidden rupture. The reality was the disruption and social impact of the dyslexia-SpLD profile was identified at age 6 in this study, but risk recognition by parents and school staff was for the most part muted, and the longer-term impact on experiences of inclusion was built over time and events which made for complexity when the need for intervention was finally recognised. The next chapter focuses upon how agency of parents, school staff, and the child can shape the development of inclusion that results from discontinuities described.

Chapter 7: Parental and Teacher Agency: A New Construction

The construct of agency in this study

The capacity to act independently, assert free will, understand the consequences of actions, and make decisions have been well recognised as core qualities of individual agency that were identified in the literature review (Griffiths et al., 2004; Kirby, 2020b; Perry, 2012). There are cultural determinants to how agency is expressed within the context of England and its education system (Cullen & Lindsay, 2019; Griffiths et al., 2004) . This chapter draws from the construct of “additional to or different from” in the SEND law (Wolfe & Glenister, 2020) to examine agency as that which goes beyond the typical levels of activity or action by parents associated with a child attending ordinary mainstream education.

However, as the previous chapter examining discontinuity reported and following sections illustrate, the boundary around what was ordinarily available as support in school was variable, was conceptually challenging with respect to dyslexia-SpLD, and lacked easy clarity for professionals and parents in dynamically evolving environments, such as classrooms in English mainstream education. This was consistent with findings from (Leitão et al., 2017); Phillips and Odegard (2017) and consistent with the work of Lake and Billingsley (2000) who examined sources of parent and school conflict.

The previous chapters demonstrated the cumulative difficulties that underpinned educational failure or rupture for a child with dyslexia-SpLD. The difficulties arose because there was a mismatch between the child’s profile, the situational demands, and the capacity of the environment to meet the child’s needs. In combination they could be considered descriptions of structural features at the child or systems level shaping inclusion for a child with dyslexia-SpLD. They predispose a child to relative underperformance in education and

social outcomes in relation to their peers (Gov.UK, 2020a). This chapter addresses how three forms of agency identified as themes from the data (compliant, subversive and forthright) exercised by parents were used. These three forms extend the work of firstly Griffiths et al. (2004) by describing a structure in terms of interpersonal relationships and secondly Lake and Billingsley (2000) by how parents' choice of strategies is linked to the efficacy of getting a child's needs met with respect to longer term inclusion. The form of agency describes why parents may transition from one form to another, and how through agency parents seek to constrain the structural framing and prospective trajectory of their child in education. The sub-research questions for this chapter are:

- I. What forms of agency are enacted by parents to try and secure 'good outcomes' for the child through access to education and long-term inclusive education?
- II. Under what circumstances, are the different forms of parental agency enacted or not, and what are the consequences of exercising agency or not?

Agency is a substantial area for consideration; accordingly, the chapter will address the following topics:

- Justification for focusing only on parents.
- What distinguishes the three types of agency identified?
- When do parents use each type of agency?
- What are the consequences of each type of agency?
- When do parents move from one type of agency to another?

Introduction

Previous chapters have raised the following key points. First, chapter 4 (Arc of Education) described the structural features of education highlighting the geographic division between home and school, and that there was no formal place in the structure for parents. Second, the previous two chapters, 5 (Visibility) and 6 (Discontinuity-Disjuncture), drew upon

both parental and school case studies to provide a rounded description using both groups' perspectives. They illustrated the different types of challenges children encountered as they tried to engage in education when they had specific literacy difficulties as part of the profile. In combination this provided the context of education for a child (and their family) with dyslexia-SpLD and explanatory frameworks for trajectories of relative failure.

In this chapter the focus is on parental agency, examining how parents responded to what they saw and understood in terms of risk to inclusion and good outcomes for their child. The parental focus reflected a gap in the literature, linked to the underexplored relevant area of how access to literacy skills was supported when school provision was failing to make effective impact. It is also the case that parents are able, in a way schools are not, to activate the legal framework to secure legally enforceable support. For instance, they are the only party who can appeal against the provision for a child determined by the local authority, the school cannot do this (Wolfe & Glenister, 2020). This was evidenced by six parents who did so. This does not take away from teacher agency which reflects both compliance and innovation as demonstrated in the prior chapters. Rather this chapter extends that professional form of agency exercised by teachers in school, by considering how parents of children with dyslexia-SpLD constructed their understanding of inclusion and good outcomes through action. These accounts were compared with teacher accounts where pertinent to build an overall construct of agency for this study that was anchored from the parental viewpoint.

This chapter draws upon three different forms of visibility described in the previous results chapters, as they addressed themes of structure, types of visibility and discontinuity-disjuncture. I have used and extended those findings with further data from the main two case studies of parents and school staff to examine how people reacted to the information they had, and what they did (broadly described as agency). The chapter will initially describe how agency was identified in the data and through a worked example how extracts were selected

for use. It will then describe and illustrate in the typology the three forms of agency (compliant, subversive and forthright) before moving on to consider how parental agency is transformed across time and events. The location aspects of agency are briefly considered before the substantive section on how types of and transformations of agency are implicated in experiences and perceptions of inclusion.

Interconnectivity of themes including agency

The data indicated that agency was precipitated by something, either direct distress or anticipatory perceptions of risk, and located in the consequential outcomes. The interconnectivity of evidence and events was one of the elements that initially made identifying themes in the thesis challenging. The material had the potential, and was in practice, to be considered through multiple prisms and perspectives, for example distress and risk were two alternative perspectives used. That process of engaging the data across a range of prisms and themes occurred before settling on agency and structure. Critical realism was helpful in its central focus on the tension between structure and agency and that captured the lived experience of parents of navigating the apparent monolithic structure of state education for their child. Using that framework, a theme of agency as it pertained to the research question was an ontologically consistent way of examining accounts from participants of what was perceived and understood. A focus on agency allowed for study coherence and formed a bridge between what was seen addressed in previous chapters, and the experiences and perceptions of inclusion considered in the next chapter.

A worked example of interconnectivity of themes and decision making

For example, at the end of chapter 5 (Visibility), the case of Parent 10 and their child and their school swimming lessons was considered. It was used as an illustration of both forms of visibility, behavioural and epistemic, but it was also illustrative of other themes. The placement in lessons with younger children was an example of discontinuity-disjuncture. It was also an example of failed inclusion in that the child withdrew from school attendance.

However, as a narrative it also captured different forms of agency. Firstly, the one Parent 10 tried to use (unsuccessfully) - rhetoric, negotiating with the school to resolve the problem she and her child perceived they had, and the refusal by school to engage or acknowledge the salience of parental information. That was an example of parental knowledge being resisted and epistemic injustice (Byskov, 2020) Parent 10 then took to acceding to their child's needs to avoid distress and keeping him off school, and the school focused on complying with attendance rules with limited impact, other than conflict (Lake & Billingsley, 2000). The forms of discontinuity-disjuncture, agency and inclusion could also be represented by other parental accounts in the case study data and so it was not unique, it was an illustration of a common pattern, a demi-regularity. So, there were multiple ways this extract could be located in the research.

However, the extract as a succinct description of the importance of behavioural and epistemic forms of visibility and was very powerful, so it was placed in chapter 5 (Visibility). In this extract/example, the final selection in the writing up of the thesis was for its use in that chapter. For this chapter on Agency the observations also informed (as an example) the common and repeated account of how parental agency could be side-lined or ignored by a school, with consequential impact. Further, that parents could take an insubordinate approach and do what they felt necessary to protect their child. This went on to contribute to formation of one of the forms of agency identified in the data, subversion. So, although not directly referenced in this chapter, the incident and account form part of the data drawn upon. Much of the data analysis for the chapter follows this pattern and extracts chosen represent themes that cut across the parental case study.

Although the preceding chapters and this one had been separated out for ease of reading and illuminating the theme; there were important associations between the features of visibility, disjuncture, risk, distress, and agency. That interconnectivity aspect is

acknowledged in the chapter and developed in the next one addressing Inclusion. The next section of the chapter deals with identification of the different forms of agency.

Defining and describing agency, how it was identified

Agency as purposeful action or non-action

Agency in this study is focused upon what extends beyond the typical levels of ‘human doing’ as a parent of a child in mainstream education. It implies a level of awareness and consciousness but recognises that in some cases such agency may be at a lower level of awareness. Most cases in the data pointed to positive doing, observable behaviour in the empirical world; but there were also occasions where the agency was a decision not to follow through with a course of action. An example of the latter was from Vera when they put on hold plans to place them outside a school’s catchment area:

**VERA: [...] we looked at moving out to one of the villages
and when we talked about this with the children, the night after we
talked about it Vince [was distressed] because he was so nervous about
the prospect of moving school, so we knew at that point....and it took him
a long time to make friends and to be confident in his peer group**

Vera’s account illustrated the complexity and costs with exercising agency and is included here to capture how the exercise of agency is rarely straightforward and that short-term costs, notably to emotional wellbeing of a child may outweigh reasonable and long-term benefits. The balance of risk is another dimension to parental decision making and action. The following section described three different types of positive action.

The typology of agency

From the data there were three forms of positive agency identified: compliant, subversive, and forthright. There was also a passive-resistant form of refusal to engage in agency/action, but that is considered as a counterpoint in this study in relation to the active agency described. The forms of agency were aimed at serving the same purpose of securing

changes in support for a child or children, enabling to access education and inclusion both in the near and longer term. However, the quality of agency had differential impact on the type and nature of support secured, the outcomes achieved, and the costs to the person, both financial and personal. This section will provide a brief overview of those types of agency derived from the data before considering the impact of their use.

Compliant agency

On a day-to-day basis as a first approach, most parents sought to exert agency through complying and conforming to the normative structures. For example, Xavier, whose 6-year-old daughter Xara was introduced in chapter 5 (Visibility), had two other sons who also had dyslexia-SpLD and he described what happened for them (**“Absolutely, so we went through the procedure and then the school was quite supportive, as far as SENCO was concerned, it was not as good”**). In that example Xavier was summarising how the family followed all the school procedural requirements and had worked through a range of external appointments, to exclude non-educational reasons for literacy difficulties, prior to school acting, **“did those tests and both of them were referred and we’ve had NHS for my boy, for my little boy [...] just to check he didn’t have ADHD because we had to check everything.”** The agency by the parent lay in activating and completing the process defined by the school, though as Xavier referenced even then the SENCO was still resistant to addressing identified needs.

Subversive agency

Another form of agency also used was through small quiet acts of individual subversion, for example Karen ‘chancing’ upon a helpful former teacher of her son Kevin (**“I just happened to bump into him and I said about the difficulties that Kevin has been having and, he said he would have word with her”**). In that case both the parent and former science teacher were discreetly operating agency on Kevin’s behalf below the radar of school processes.

Subversion in both the parent and school cases was attributed to strategies that avoided direct confrontation on the issue but sought to circumvent or blunt perceived or actual barriers; ones that were generating risk to good outcomes or inclusion. Those barriers in the data included key gatekeepers such as SENCO or headteacher or, as part of a wider culture held by the social entity that was a school, not recognising dyslexia-SpLD as a diagnosis. That was achieved by utilising accessible resources and influence, including those outside the school hierarchy. An example of this was when Tracy was unable to engage her son's school **"By the time he was seven, I'd borrowed some money off my dad to get him diagnosed as dyslexic which we did, that was Year 3, and they were still not interested, the teachers didn't seem to have any knowledge about dyslexia whatsoever and then I found this [support service]"**. While Yvette experienced agency directed by the supply teacher to examine supports outside the school:

Yvette: [...] so he had a supply teacher who was amazing, and he said at a parents' evening I strongly believe that he's got dyslexia [...], the supply teacher did was say don't just concentrate your efforts within school, reach out and see what else is available to you and, because of that, we found the Dyslexia Association, and so Yves's spent about three years going to the workshop [...], getting a lot of support there

The parents' evening exchange was illuminating for it captured nuanced evidence of teacher agency. A reading of the account suggested that an outsider to the school (supply teacher) had made an assessment of the institutional limitations of the school culture around naming dyslexia-SpLD and capacity to provide for a child with dyslexia-SpLD. He then indicated that implicitly, while he suggested urgent action to be led by parents which was also about avoiding confrontation with the school. The teacher seemingly used a scheduled opportunity (parents' evening) to deliver non-conforming important information, which sought to empower parents and provide advice outside the established framework; that is subversive.

In combination both compliance and subversive strategies formed in most cases the utility approach parents (and school staff) activated as they endeavoured to navigate the education system and secure support for their child. Karen's account was an example of how a parent had used social connectivity skills as a tool to facilitate change, rather than challenging the teacher/school directly. Another frequent subversive strategy identified in the data was to secure support or assessment out of school (as suggested by the teacher in Yvette's case), rather than confronting the school. School staff engaged in similar strategies or worked around school hierarchy providing support.

Forthright agency

Alternatively, agency by parents or school staff was forthright and direct in challenging structural challenges and resistance around progress, inclusion and need for a child. Notably where schools and staff were acting as a socially coherent entity by applying official or unofficial policy. But it also occurred when school staff had to challenge the child for seeking to conform to peer expectations thereby rejecting 'help'.

An example of a parent challenging the school was Beth. Unusually for parents, her style was forthright from the start when she notes within weeks of school starting her son was having difficulty with basic literacy and maths tasks.

BETH: *they came to kind of maybe 4 letter words, he was struggling with those, so like within 3 months I had gone in and they had said: 'No, you know, it's ok, it's ok' but then you know I kind of persisted a little and then he was put on his, I believe, but my memory is not very good, his first IEP in reception*

However, matters did not improve as she recounted:

BETH: *but then come Year 1, 2 that total washout, putting notes in diary as to how disappointed I was that Bob was coming home with so little understanding of what he was doing in school, totally white-washed him. I felt they kind of...disregarded any problems that they may have had...*

Beth continued to challenge the school, against much documented obstruction from the school; for example when the school attempted to stop the Local Authority Educational Psychologist assessing her son (**"the Ed. Psych. came in and Bob was in one of his one-to-one sessions and they said: 'Oh well we can't take him out' I said: 'Excuse me, I'm his mother, I said you go and get him from that class now and you bring him here'"**). By this stage her agency was both forthright and explicit. Eventually she did secure a Statement of Special Educational Needs, for which she had to do two tribunals to secure all the support. In the following extract she recounted how she challenged the school in a legally constituted review process. **"So, I went to Bob's annual review last month and I stated in school that I'm very unhappy with his progress"**. This was an unambiguous challenge that had legal weight, occurring at point of formal intersection between parent and education system. Beth's voice had to be acknowledged and responded to in that setting. That communication history contrasted with Tracy's experience **"By the time he was seven, I'd borrowed some money off my dad to get him diagnosed as dyslexic which we did, that was Year 3, and they were still not interested"**. There were no observed major social differences between the mothers. Beth however had accessed some additional support to help her learn how to navigate the system.

An alternative form of forthright agency was when schools, parents and children worked in synergy to secure the assistance. An example of that was from Parent 9 one of the talking about the school and child's combined efforts to secure access to education: **"Just lots of little things to try and say to the kid, look you do this and I'll do that. So, in science where things move very quickly, he will often do the experiment while somebody is scribbling notes for him"**.

The illustrations were exemplars of three broad types of positive agency found in the data, but there was also negative agency as a form of resistance when action did not occur. An

example of that was Lucy's case and the failure of the SENCO to record or act on the information provided by Lucy about her son Larry's needs **"If you typed his name in to his student profile it just came up with a little picture of him, it didn't have anything, nothing"**.

Transformations in Agency

The three forms of agency identified from the data were used over time to seek to or secure support for inclusion and educational access for a child. Across the data, while a parent may have demonstrated a preference for a style of agency, for instance Beth had a pattern of forthright as illustrated previously, they made use of a range of strategies. This occurred in a transformational and sometimes intersectional manner, where more than one strategy could be used across the span of the Arc of Education or in different sections of the Arc. This section examines why a strategy was used or changed and what the impact of that choice was. However, first an example of transformation and co-occurring agency is provided through Nora's account.

In the following extracts Nora recounts how initially, she went through a range of processes and accepting proposed add-on programmes to mainstream ordinary education (OE) for Nathen, as a form of compliant agency which ranged from the school looking up online **"they did a bit of research on Dyslexic Action, well I thought they'd actually contacted them or they'd gone to see them but they just did a bit of research online and just said oh let's try that, it was like..."**. This however was in the context of having already secured additional 1:1 teaching **"We started that [outside tutor] in [Year] 3 or 4. And he'd go for an hour over the week, and she was mainly doing a lot of overlearning and supporting with assistive technology"**.

Nora persisted with a mixed agency strategy. At various points she used forthright agency, for example round Nathan's placements in bottom sets **"and we kept saying can you move him up in PE because it's not as if he can't do PE, he's quite good at PE but they said**

we think if he's in the top of that group, that will be good for him", which like Tracy and many parents in the case study their viewpoint was overridden and dismissed and was being ignored (as captured in the quote; Nathan was very good and went on to get PE based qualification in and out of school). In parallel she also used relatively subversive strategies with respect to the secondary school. While she and her son were going along with the school and their provision, it was evident that it was not meeting Nathan's needs when he observed about his peers **"Some of the kids he was with in the bottom set, there were a few which he found, some of them funny but they could be quite disruptive. But he said, 'you know, they can't help it mum because they're special'."** It's perhaps not surprising after this history, having tried and not succeeded to get the relevant support, Nora took to the ultimate form of subversion which she converted into forthright by not confronting school but rather by consulting solicitors. Subsequently that culminated in the following exchange with the local authority, and example of disjuncture and forthright agency:

NORA: They said 'if you'd like to keep him in mainstream'. I said 'yeah, that's great, if it works', and I said 'it clearly isn't working, and it clearly hasn't worked'. She said 'for you to get us to pay for a special school, we would have to lose', and I said 'okay let's just do it'.

Nora's account demonstrates the flexible approach of agency that could be applied. It also alludes to the way perceptions of lack of progress, meeting need, or inclusion were the triggers for each type of strategy. In summary, when progress was not ensuring good outcomes through effectively meeting needs, then parents who were alert to that aspect, engaged agency.

Temporal aspects of agency transformations

Some of the strategies seemed to be closely aligned, for example compliant to subversive was a common transition while compliant to forthright less so. The transition from one to the other was progressive and largely followed the pathway of compliant, to

subversive, to forthright, and then largely back to compliant in this data set. Agency was an emergent property from the context the child was working in, and the perceptions of access to education, inclusion and risk, as the following extract about provision of technology to support her 8-year-old son in class from Wendy indicates.

WENDY: *one of the things that he needs is a keyboard, the school has gotten rid of all its laptops and apparently, this is gossip rather than fact, the head teacher is moving towards iPads and isn't going to replace the laptops. So, we're at the point of having to have another conversation with the school and it may come to us talking to the headmaster.*

Wendy's extract records a process of evaluation of action/response occurring before changing agency strategy ("**we're at the point**"). She was already supplementing school teaching of core literacy skills and recognised for her son that technology was going to be part of future solutions. The extract suggests that she was already using subversive strategies but was ready to move to forthright agency. The passage of time implied in the extract and monitoring came with a state of alert for the parent aware of the wider context ("**apparently, this is gossip rather than fact, the head teacher is moving towards iPads**"). That guarding of and attention to their child, was replicated when the initial phase one interviews were subject to word frequency count and the word 'Think' or variations of it dominated the resultant word cloud (see appendix A).

Across the parental case study accounts, temporal drag was observed between when accounts of a problem or difficulty was observed as a source of risk, and later action taken. Beth was unusual in the speed of her response ("**so like within 3 months I had gone in**"), generally in the data there were substantial gaps of school terms or in some cases a year or more before action was taken. For Beth, her personal context may also have given her access to appreciation of the variance on development and the need to intervene. Nevertheless, even

with forthright agency in her case it only produced limited help, initiated after time, and Beth ended up funding additional out of school support for basic literacy. This transformation effect of agency was easier to see in the data when children had been longer in education, parents had more experience of the limitations of early strategies. This was clear in the longitudinal study and in the two additional cases in which each of the parents had exercised the most explicit of forthright agency in securing legal protection.

BETH: so like within 3 months I had gone in and they had said: 'No, you know, it's ok, it's ok' but then you know I kind of persisted a little and then he was put on his, I believe, but my memory is not very good, his first IEP in reception

For many of the parents something of a developmental curve in agency occurred over time. This ranged from initial compliance to a range of activity supporting their child, as they became increasingly assertive when observing a lack of their child's progress, or their distress and were meeting resistance. However, as both chapter 5 (Visibility) and chapter 6 (Discontinuity-Disjuncture) illuminated, the domains of concern were not just reading/writing/spelling. They also encompassed aspects such as social inclusion/ bullying, lack of confidence, lack of common parity with peers, lack of integrated identity, as well as being located with groups they did not -identify with, exemplified and illustrated by Nathen (earlier in the chapter) and Xara (chapter 5). The other sources of action were the stresses and strains within the family home linked back to distress from school.

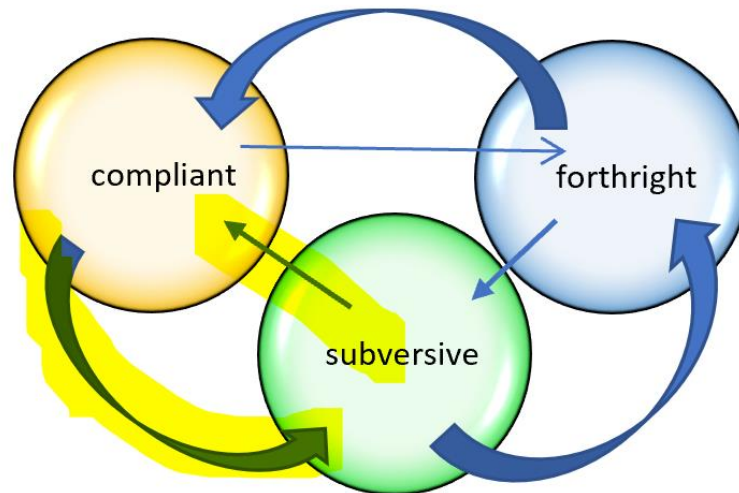


Figure 23 Transformations of Three Forms of Agency. Representation of types of agency and their intersection to each other derived from data analysis of both parents and school case studies, the major arrows are the usual paths of transformation. The internal arrows capture other pathways in the data, with the highlighted one indicative of the most common combined route in the data.

Risk, distress, and agency

Risk to education and health, or contingent distress are some of the most significant social impacts of dyslexia-SpLD and dominate the grey and qualitative literature of the field (e.g. All-Party Parliamentary Group For Dyslexia and other SpLDs [APPG-Dyslexia &SpLD], 2019a; Brown, 2020; Bull, 2009; Zambo, 2004). As discussed in the literature review, Riddick (1996); (Riddick, 2010) explored the social and emotional aspects of dyslexia-SpLD. What was striking in the data from this study was how little had changed from her accounts since 1998, and 2012, and that the kinds of statements made by parents in this study, were found in Riddick's work, and were also found in Levi's study of 2017 in Australia. They seemingly represent intractable features of children in formal education with dyslexia-SpLD. What has not been examined to date is how the psychological state of parents and child facilitate different types of agency in the pursuit of resolution. The focus of this subsection is on that specific aspect.

This section will evidence that one of the findings in the data was the importance of distress as a precipitant to agency, and how continued distress maintained and transformed

agency style. The study also identified how when distress abated agency was depowered. Emotional distress and consequential impact on the family were persistent features across the data and that parents' emotional wellbeing (or lack of) was a significant motivator for parental agency. Difficulties with academic progress/literacy was not itself sufficient to move beyond compliance or subversion forms of agency. That constrained options for changing outcomes. This section will draw on the account from Yvette as an exemplar that captured a wide array of aspects of common reoccurring parent experiences, but also usefully demonstrated the role of child distress in parental agency. The features discussed from Yvette's account was illustrative of wider findings in the parental case study. Yvette's accounts are supplemented by other parental contributions where useful to do so.

Yvette and the role of distress in agency

Yvette was the mother of two children, a boy Yves in Year 7 and girl Yasmin in Year 4, at time of interview both had dyslexia-SpLD. Her account captures the way perceptions of child distress differentially shaped her perceptions of need and inclusion, responses and agency. For her eldest son who had conveyed distress and was being bullied she took an opportunity to move school. In contrast she took no action for her daughter attending the original school as she was seemingly socially content although making poor academic progress. The extract starts with the school SENCO who was the Year 2 teacher recognising Yves' literacy difficulties but not engaging:

YVETTE: *Really frustrated, and we knew ourselves that there was something, but it almost felt like a your child's not performing very well, but 'we're not going to explore it and we're not going to do anything really to support it'.*

I: *Did you get out of her why that was the case at all?*

YVETTE: *No, not really, no, it was just like Yves's not doing very well, and so at that point I started doing a lot of research and came across typical symptoms of dyslexia and dyspraxia and things like that,*

and to me that was a lightbulb moment, I thought yeah this really does fit, I mean not everything obviously, but I could see him in those lists.

[...]

YVETTE: *[homework] Yeah, absolutely, and it would take four or five times longer than you thought it should take, but from that point on we just tried to be really, really patient, and he'd lost a lot of confidence even at that stage.*

I: *Okay, so this was by Year 3, or still ...?*

YVETTE: *In Year 2, yeah, I think he knew that it wasn't going well, and he was quite demoralised as well.*

In ways previously noted from data in other chapters, children in Year 2 were experiencing the impact of their inability to acquire core literacy skills. While parents noted difficulties in the early stages, across the case study Year 2 was an inflection point where for most parents' alternative strategies and agency emerged to the front and often linked to their child's self-awareness of struggling. For example, Xara's reported reference to her being in the "dummies" group. As observed in other accounts by that point there was evidence of collateral damage to confidence and social being. Most parents such as Susan recognised difficulties prior to starting school, for example **"We always thought there was something not quite right with Sarah [...] she'd never count. You'd go one two three four, she'd get to three and stop [...], we always felt that there was something stopping her because her conversation skills were brilliant"** while others it was later. In Yves' case the mother had recognised differences but not been able to clarify the 'why' and that persisted through foundation and Year 1.

Up to this point of Year 2, Yvette had gone along with the school, but this was now into the third year and Yves had not made progress. The psychological toll on her was indicated by her comment on being **"really frustrated"** indicative of resistance and

powerlessness to effect change for Yves. In the following extract Yvette describes her emotional reaction to the school's refusal to engage with Yves' difficulties, to ignore her child's needs and obstructed communication. She described aspects of those difficulties. The emotional cost to her across his primary school was high, at the end of the interview I reflected and checked back with her to share my perceptions, and she had this to say:

YVETTE: ***[...] and with primary school, they wouldn't even give an email address for us to contact them or anything like that.***

I: *Wow*

YVETTE: ***Yeah, literally.***

I: *I kind of, I mean in asking the questions I was asking about the primary school but I also sensed with you it was like 'this was so bad I don't want to talk about it', so I felt a bit constrained, you know, can you tell me about this, 'it was like actually I'll just keep clear of it for a bit', but is that accurate, is that how you felt when I was asking the questions?*

YVETTE: ***Yeah, really.***

I: *Yeah, it was like 'actually no I just want to leave that'.*

YVETTE: ***Very dark times with him, yeah. [Yvette held her body tense and looked away]***

With the move to a new school that had from her account a sympathetic attitude towards diagnosis ("**they're dyslexia friendly anyway**"), Yves' situation improved and Yvette's stress abated with free flowing communication between home and school ("**Really good, we email quite a lot**").

The above extracts from Yvette illustrated many recurring features in the case study accounts around visibility and responsiveness to it, the consequences of failure to mutually agree what the level of difficulty was and what action was needed had wider resultant impact, as was also found by Levi (2017a) in her Australian study. The consequent lived realities further provided drive for agency of bullying ("**he got a lot of bullying**"), distress ("**he was quite**

demoralised”, “I mean we used to constantly get I don’t feel well, I’ve got tummy ache, I can’t go, blah-blah-blah-blah”) , parental distress (as above), being overpowered by the work commitments e.g. homework (“**massive clash points over homework**”) and parents being blanked by schools and barriers to communication (above). Those extracts are taken from Yvette for consistency, but they were all as topics found persistently across the case study interviews. They formed the consistent social account background of dyslexia-SpLD. In all these scenarios the parents were being directly impacted by the child’s distress which was in response to the experiences anchored in school and back to difficulties with literacy skills and attainment. The parent’s action was broadly directed to that area either through school or through outside teaching and support. As Yvette observed the “**workshop on a Saturday morning, getting a lot of support there, and I think that’s where he has caught up with things like his spelling, it has been really, really, really helpful**”. Nevertheless, Yvette moved Yves’ school. The additional sessions were not sufficient on their own to address the wider social and educational inclusion impacts, although they improved skills useful for longer term senior school and post school inclusion. This need for a second stream of education however also represented a lack of inclusion on many fronts both for the child and the parent. By implication parent’s and child’s membership to their wider school community was also challenged. Both by the experiences they had in their shared common space of school life and progress, with respectively other children or parents, and the relationships with school staff.

Yves and perceptions about risk and capacity

For Yvette, she understood that her child had intellectual capacity and that as things were being left to the school that potential would not be realised. But, so did Yves. He was reported to be demoralised in Year 2 and later Yvette recounted “**he got a lot of bullying for his dyslexia, there was one child in particular he was like you’re so stupid, you’ll only ever be a postman when you’re grown up, things like that**”. That Yves reported this back indicated it

was a construct of inclusion that extends beyond the Arc of Education and into the identities and roles of the adult world.

Once schooling and support was changed, there was a shift both in Yves' state and the kind of agency Yvette had to exercise which was respectfully forthright on both sides.

I: So would you say home life is a little calmer?

YVETTE: Yes, oh yeah I would do, yeah. We don't have battles over things like going to school in the morning, he gets up quite happily and he just trots off, and he's happy.

One interpretation of the extract was that Yves himself did not perceive the environment to be a risk to him. Yves was still accessing mainstream education. This evidence of how a change of school had marked impact on Yves confirms what is commonly understood from the Ofsted and school census data discussed in the literature review; namely the salience of the educational institution (Ofsted, 2020). Ordinary Education (mainstream) is a broad construct that for typically developing children will be relatively consistent in providing access to education, save for the wider social economic disparities (Johnson, 2020). The findings from the data partially from the evidence of where children moved schools suggests individual variability between schools has greater impact on children with dyslexia-SpLD than would be expected. Yves' new school had a different cultural orientation to the identification and diagnosis ("**they're dyslexia friendly anyway**") and the links between the culture of the school, risk, parental agency and distress are for consideration in chapter 8 (Illusion of inclusion).

Yvette's history of agency

Yvette's history demonstrated a developmental arc starting with compliant agency, but the trajectory was modified when the supply teacher provided validation of her suspicions and signposted resources ("**so we're really grateful to that supply teacher that prompted us**

to look at that.”). With this she moved to a subversive form of agency which was a parallel education provision. However she then progressed to a forthright agency of moving schools when she determined that even with her outside support (**“We decided, because he was so unhappy, we decided to move him for Year 6”**), that inclusion and progress were so impaired that his distress was too great. From this viewpoint agency was a progressive hierarchy of increased activity challenging structural features. Starting from her Year 2 experiences there was a process of self-education, inquiry and to engage support out of school with a specialist teacher. From Yvette’s perspective that was successful in moving Yves onwards to a degree, the individual intervention and change of school improved literacy but still not meeting national thresholds (**“He didn’t achieve his SATs in English and maths, he was quite close with the English, but I think he got something like ninety for the maths and he had to reach a hundred to pass it.”**).

In that respect, prior to the transfer she was engaging in subversive agency, not out of deference to the school but rather because the school refused to engage, and she perceived long term risk. It was a matter of two parallel education provision/services, however without integration and reinforcement. That had several implications and costs which will be explored further on. In so much that this reflected the common accounts in the data but also in the literature, it is a story that has consistency, not only in England but wider afield such as Italy and Australia (Barbiero et al., 2019; Leitão et al., 2017). However, the relevance of the account above is how it contrasted with Yvette’s other child, her daughter Yasmin. Yvette’s account of Yasmin threw into sharp relief some of the causal assumptions and links between educational attainment and progress and disruption of inclusion, and this is the focus on the next subsection.

Yvette’s Daughter- a different educational experience

The importance of distress as a motivator for agency is illuminated when Yvette’s daughter Yasmin’s case is considered. In the extracts below, Yvette firstly describes Yasmin’s

social presence, but then goes on to identify the problems with learning and that no additional support such as extracurricular lessons had been implemented. Despite this, Yasmin has remained in the school. It was not clear what alternative options on schooling were available for Yasmin. In the final extract Yvette summarises her position and how her agency has essentially become a disengaged form of compliant. The potential long-term costs for Yasmin are different to Yves.

I: So it's interesting for your daughter, it sounds like she's got more friends?

YVETTE: *Yeah, she's a real social butterfly, she really is, that describes her totally.*

[...]

I: So she's got dyslexic tendencies, and how does that manifest for her, and I take it she's not at the original primary school or is she still?

YVETTE: *No, she is there actually. She has had a far better experience with the school, largely because she's in a very nice class with very nice kids, and she's very different to Yves, her reading's never been as good as Yves's, she's struggled more with it, and her spelling is far worse than I think Yves's has ever been.*

I: Right, okay.

YVETTE: *Well, is that true or not? Her spelling's worse at this point than Yves's was when he was her age, so she's in Year 4 now.*

[...]

I: Given that you've got that ahead of you, what is it that you want the school to do?

YVETTE: *I don't really know, I've almost written off her primary years because from speaking to other parents everybody just says you'll see a massive change when you go to secondary school which is what's happened with Yves, and everyone says you just do not get the support in primary school, you've just got to get through it and then hope that things change when you get to, it sounds really defeatist when you actually say it out loud but I'm not, I'm just not expecting a lot from them.*

The contrast between the account of Yves and of Yasmin above was important in this study for this was differential decision making within the same family unit. Yvette's account of her actions with respect to her daughter Yasmin illustrated she had disengaged from the type of active agency of either subversive or forthright form enacted with Yves. This example demonstrated that there was not necessarily direct causality between literacy difficulties, poor quality inclusion and distress, assumptions which populated much of the grey literature. What the contrast between Yasmin and Yves educational management did was illuminate that distress in the child was an important mediator of parental agency both in form and substance. As will be discussed in the sections on the costs of agency, Yvette also had financial constraints when she discussed why she had not continued teaching for Yasmin **"on financial grounds because we had to pay for it which is a lot"**, but it also suggested how parents (in this case the mother) perceived longer term risk which was anchored in emotional wellbeing rather than academic core skills. However, the real risk to longer term social inclusion shaped through exam portals was in literacy skills and educational access.

I: Had you thought about moving her to a different school?

YVETTE: I think I'd be more inclined to if she wasn't happy, she's got a really good friendship group and everything like that, she's very, you know, we don't have the same issues that we had with Yves like 'I really don't want to go to school', things like that, which I think is a big thing, I think being happy at school's really, really important.

Yvette reported that from educational access and progress her daughter was in a worse state than Yves, but despite that and illustrated above when she talked of **"written off her primary years"**, Yvette had not activated out of school tutoring, sought to challenge the school, or seek alternative schooling. The impact of dealing with Yves had seemingly drained her capacity to express active agency. She appeared to have hope or expectation that senior school could address problems that primary education had failed to across 7 years. Further,

failing to note that with respect to Yves her own additional support would have in all probability played a positive contributory role. The core of the difference was that as she noted that Yasmin was not notably expressing distress, she did not perceive disturbances of inclusion she had for Yves.

YVETTE: *I don't know how to describe it really. She's not as noticeably bright as Yves, like her conversation and the things she's interested in aren't anywhere near as advanced as he was at her age I would say, but she just seems to get on with school life a bit better, she doesn't rail against it in the same way that he did.*

Yvette's extracts are cumulatively longer and more complex than other extracts utilised in the study write up and to justify such presence needed to have an associated significant contribution. They were important extracts; for the purpose was highlighting the multifaceted nature of agency by parents in relation to their children, which went beyond reductive causality. It unusually demonstrated that academic attainment and distress were independent factors in relation to agency; but it also suggested by comparing the activity of school and parents towards the son and daughter, how gendered positions in education may also impinge on type of agency activity and decisions utilised. The latter point will be explored in greater detail in chapter 8 (Illusion of inclusion); however, it is put down here as a marker with respect to agency.

Yvette is an exemplar of other cases in the data for firstly identifying that educational risk alone was insufficient to power effective agency to resolve difficulties, rather the combination with distress appeared to create tipping points in transitions of agency form - compliant, subversive or forthright to another. It was also the case that reduction in stress seemingly depowered agency level. Inadvertently generating realistic additional longer-term risk. One aspect captured by the account is the indicators of the gendered aspects of dyslexia-SpLD, and that quality will be picked up in chapter 8 (Illusion of inclusion). The depowering

aspect was also located in other accounts for example in the first extract above from Beth in the chapter.

Karen and Beth: accounts of linking action to distress

Karen's account reflected why the link between type of agency and distress may have been more difficult to identify in previous research, as it represented a patchwork of partial accounts and information that needed to be linked up. The accounts could start taking a chronological structure, but that further material was introduced out of sequence. That was true of all the parental interviews (teacher staff interviews were less concerned with personal history, so this was not such a common feature) and the relevance of various disclosures was apparent in the analysis phase. As indicated in Yvette's extract previously, there were also sensitivities and ethical considerations about how far as an interviewer I could probe information, so for most interviews there were aspects that had to be left underexplored in this study. Collectively the extracts also illustrated difficulties parents had in gaining a reality-based evaluation of risk with respect to the impact of failing to secure literacy skills in a timely manner at various stages of education. That was a persistent feature across the parental data and realisation may, like Diane in chapter 5 (Visibility) and others, come too late to secure good outcomes.

BETH: and this is around the time that I maybe sat back on my laurels a bit because he was happy, he liked the teacher and he was making some progress, not vast amounts of progress ...

KAREN: [...] I think he got to probably, Year 4 and I really started to think "I'm really worried, he doesn't seem to be picking it up". Not to compare him to my older child but that's the only comparison I've got, and he doesn't seem to be getting this. I went back into the school and they said "Oh yes. We've noticed some things as well." The school started putting extra things in place, more phonics and they started doing other things as well.

Beth's account has clarity in how even the minor shift towards positive emotional wellbeing of a child could depower active forms of agency, such as the forthright one she had been using in communication with the school (while maintaining out of school support activity). The extract illustrated that her perception of risk was muted in those circumstances. That situation did not survive through Year 4 and both emotional wellbeing and educational attainment were challenged. By the end of the Year 4 she had secured a Statement of Special Educational Need.

For Karen she too had delayed action, she had expected Kevin to 'pick things up' but Year 4 is late in the process when the research strongly promotes early intervention (M. J. Snowling, 2013). Later in the interview she described the significant family stress around Kevin's behaviour, which put her actions into context. Indeed, as will be discussed in chapter 8 (Illusion of inclusion) she alluded to the conflict between parents that precipitated the need to engage in forthright agency ("**I went back into the school**")

KAREN: *Around that time, yes, when things upped a level. His behaviour. And his behaviour at home was awful as in tantrums,*

But in between those two extracts which tell a coherent account that was a contrary one.

KAREN *He has always had a nice group of friends. At primary school he had a really solid group of friends. [...] He did, and I never worried about him socially then. He was certainly part of that.*

KAREN: *there's a reading shop in [town] and, I had taken him there at the earliest time they were taking them. I can't even remember what age that was, and nothing came out of that.*

Then as the interview progressed towards the end.

KAREN: *It was quite, I think it was quite significant. And now, they have just done some reading and he is at a reading age of eight and he is thirteen.[...] I didn't realise he was as far behind as that. So, that shocked me this year*

One of the values of open interviews is that they allow exploration of topics, but they also convey how participants' stories unfold in nonlinear fashion as they evaluate how the conversation is developing. Parents in the study like Karen had experience of being judged unfavourably and were naturally predisposed to caution. The distress experienced was a source of pain in memory and recall that was repeatedly observed by me as the researcher. Fortunately, a professional background in mental health work and my own experiences of dyslexia-SpLD did provide skills to manage the situation with sensitivity.

Identifying links between agency and distress

The wider context of Karen's agency was dissipated throughout her interview. Initially like Beth she had observed difficulties in key stage 1. There was marked literacy and number problems, which contrasted with Kevin had good verbal skills. As time went on, she engaged in paid out of school support ("**reading shop [...] I had taken him there at the earliest time they were taking them**"). So from an early stage Karen was using subversive strategies as the school were not acknowledging concerns ("**When I did mention it, they said 'No, I think his letters are fine'**"). However, it was not until Year 4 that she challenged them directly and more was provided (discussed in chapters 5 (Visibility) and 6 (Discontinuity-Disjuncture)). The context surrounding the extra provision was an account at home of substantial distress and emergent school resistance/refusal. When that was subsequently disclosed later in the interview it illuminated why Karen had then changed strategy and engaged in forthright agency during primary school, and later did so promptly in response to Kevin's difficulty with science lessons. However, the overall picture presented was of a social child happy at primary school, and the shock came when in high school he was found on assessment to be 5 years behind

chronological age for reading. At that point perception of risk by Karen was transferred to longer term outcomes:

KAREN: *So, that shocked me this year because I, we are trying to say to him that you have got to do your best to get a level four in this and I know that's going to be hard.*

However, she went on to reflect with frustration **“At not one stage did they tell me that they were concerned about where he was. And so, that sort of lulled me into a maybe it's quite a mild”** again the lack of distress either generated by the child or an appreciation of the severity of Kevin's difficulty depowered her agency. However, the shock of his degree of difficulty and impact on long term education outcomes left her seemingly overwhelmed, a point that will be picked up in the next chapter. She again returned to prioritising emotional wellbeing **“For me as a parent, as I say, I am really working on the whole self-esteem and just keeping his confidence and he will say “I'm good at science. I'm good at this.”**

Parental privilege of emotional wellbeing

Across Karen's and Yvette's accounts as well as Beth's, there was an illustration of how emotional wellbeing was privileged and how there was variable recognition that educational progress was a long-term risk. Both shaped the forms of agency parents used to seek resolution of their child's difficulties. The account demonstrated the flexible application of different forms of agency around the level of distress, disruption, and risk that was perceived, with the risks from lack of early literacy progress poorly understood.

Parental agency in relation to academic progress

Risks to long term educational access were evaluated by the researcher as generally difficult for parents to judge as exemplified by Karen's response above and by Diane's extract of having regrets and wishing she had acted sooner. However, while emotional wellbeing was as demonstrated an important driver of action, higher up the span of education in secondary

concern on educational access and progress was also a contributory feature and forthright agency was visible in those situations.

For example, moving schools out-of-phase of education occurred in the data with 9 of the 18 families doing so. While that may have been driven by emotional wellbeing, failure to make what was deemed appropriate progress or access support was also part of the context. Within the data was an extreme example of direct action of not only moving schools but localities into different administrative areas to secure appropriate support (parent asked not to be identified in relation to this statement):

“I think the fact that we moved area tells you quite a lot. I did not feel there was any mainstream provision where we were living that was suitable for him [...redacted] and I felt that after, oh gosh one and a half years, I just was not comfortable that they were doing what he needed. Now some of that was not the school’s fault, some of that was the fault of [Local Authority A] who will not provide tech to children”

Both lack of awareness of how current progress fitted (or not) with longer term skill needs, and reluctance to act were themes found across the parental data. Key points of segmental change, notably secondary transfer did prompt evaluation. As Karen noted in chapter 5 (Visibility) getting such assessments such as the literacy/dyslexia-SpLD one took a great deal of effort and delay:

KAREN: They said, “you can pay for it yourself”, and I thought, I could have paid for it myself and I would have but, I just felt, and I don’t know if this is true or not, but I really felt I wanted it to come from the school. Because I felt I would be classed as some middle-class mum whose child was underachieving and I just felt strongly that it would hold more sway if it came from the school. So, I asked them and eventually, they have a got a really good teacher and she said that she had got them to do it but, it could take eighteen months. I said “look, as long as it’s done by the time [transfer to next school], as long as it is done”.

In the account above two aspects are of note. Firstly, that Karen recognised that there was a credibility issue with who produced the evidence and diagnosis (“**that it would hold more sway**”) for the school, despite this not being lawful under the CoP (Department for Education, 2015). Secondly, that of the choice of agency she was presented with by the school was to be compliant or subversive and pay for the assessment herself, but also risk it being rejected or devalued; alternatively to resist the school’s refusal and engage in forthright agency though use of rhetoric to secure the assessment. Even then it was delayed across two academic years (“**it could take eighteen months**”) to secure. The lack of clarity from assessments not being completed in a timely manner meant important facets of Kevin’s profile remained unarticulated and unacknowledged to the parents, the school staff and to Kevin and the consequential lack of effectiveness in provision, reflected in his later failings of literacy.

Awareness of risk to a child’s educational access and inclusion at secondary transfer from ongoing literacy difficulties was seemingly perceived by parents. This finding fits with the shift upwards at age 10 (Year 5) seen in the analysis of the national census data (Figure 5) that occurs close to the transition and onwards through secondary school. Unlike other Special Educational Needs, the trajectory does not stabilise or shift downwards but ascends in line with age and presents as the most common cumulative need at age 15.

Transfer to high school was a particular segmental jump that focused attention. While there was a mixed picture in the parental accounts around diagnosis, there was a pattern of reluctance by schools to engage in assessment and diagnosis. This led to parents seeking to get clarity through external assessment.

In common with other accounts of change in agency, parents perceived their voice or knowledge were not being acknowledged. The issues they raised were in seeking enlightenment through assessment and associated explanatory framework, to what they saw

as confusing and contradictory presentations of difficulty and distress for their child (Ingesson, 2007). Parents either applied forthright agency like Karen and Oliver to secure assessments through school, or they pursued outside support to achieve the same aim. Importantly the purpose of an assessment was not viewed by parents as a description for the moment in time, it was not just a label, rather it was for the longer-term navigation of the system, a tool with many uses, as exemplified by Oliver in the extract below:

OLIVER: *[...] Now Owen who we spotted first in Year 5, [...] We pushed very hard with the school. 'Too expensive, too expensive', 'right where is it, we'll pay for it', 'no you don't have to', 'well then you do it', 'oh well maybe next year when we've got the budget', 'well you're either going to do it or not'. So it was meeting after meeting with the head teacher being a case of well you say he can do better, you've got to get on his side and help. So we got that done and a statement done, went into secondary school.*

I: So he actually got a statement.

OLIVER: *Yeah you get a report back don't you, not a statement sorry, a report back with recommendations in there. He had, I can't think what you called it, the learning plan Owen had that learning plan. So that went into secondary school,*

Oliver's account was of persistent forthright agency to secure the assessment. As noted in the structure themed section Oliver, who hailed from a business background, had bypassed the SENCO and dealt directly with the head-teacher, recognising the relevance of the role and control of finance to get the assessment. Parents such as Oliver who engaged the head-teacher and a wider array of school staff were more effective in securing support. Their agency was both in engaging the range of staff, which presumably gave a wider array of information for them to draw upon in building an understanding of need. Oliver was forthright and like Karen secured an assessment, but the significant costs were ongoing out of school where he also used his own resources.

OLIVER: For example we pay for extra lessons for Owen three times a week, Oscar comes here plus does something else but that costs us about £500 a month.

Costs of Agency

The context of costs, the wider picture

The focus in the chapter so far has been on defining and describing agency, and then the situations, observations or understanding that precipitate transition of one form of agency to another. Each of the approaches to agency carried with it either direct or implicit costs to the child and the parent and that is the subject of this section. In the extract above Oliver identifies the approximate £6000 cost per year to provide support for his boys and reflects that he is fortunate to be able to sustain that support. The demands on resources were a recognised limitation on agency which Oliver recognised provided unequal opportunity **“So you take your child out of a city centre location where they can’t afford to feed them, they’re always going to hit the lowest possible mark”**. In this respect parents with capacity seemingly carried a sense of guilt that they had managed, or that they were asking for more to be provided to meet basic needs, knowing others were not as fortunate.

Indeed, the reluctance to make additional demands on the system and notionally asking for more than their perceived share, despite rising concerns, was a tension and sub-current in their narratives. That was true at least for their early stages of identification and engagement with the education system and reflected in parental notions of inclusion, as discussed in the next chapter. The research was conducted with parents that had commitment to their children, who could give important insight of the world and experience of children with dyslexia-SpLD and their families. It was therefore useful to get an outsider perspective to place that in context. Imogen a relatively newly qualified SENCO in a socially and economically challenged area provided a counterpoint. She noted that both resources and prioritisation

played contributory roles in parental agency and capacity to address the impact of policy decisions regarding identification.

IMOGEN: *that's because it's not diagnosed locally, parents have to pay for it privately if they want a diagnosis, or that's the information that I have been told, and we don't have, living in an area, well working in an area where the children are living it's not affluent as such, there's a high level of affluence but parents just can't afford it. [Further on in topic discussion] Yeah, I can't say it wouldn't be viable for everybody but on the whole it wouldn't be a priority as such.*

The relevance of Imogen's contribution for a chapter that is focused upon parental experiences of agency is that it illustrated several features around agency identified in the chapter so far from a different perspective. First, Imogen observed that parents needed to prioritise education over other demands, and that culturally that may not be so in her area, so agency had costs. Second that the level of agency required to overcome structural features such as policy of 'dyslexia non-recognition' were considerable. For some of those parents the resources required were beyond their means to meet. The weighing down of agency by increasing the cumulative personal and economic costs in exercising it meant that the children and families were limited to what was available. As Imogen went on to note a lack of clarity through non-diagnosis had costs of lack of efficacy at sensitive periods of learning which had narrow windows of efficacy:

IMOGEN: *Yeah, we haven't got anybody in our school that has been diagnosed with dyslexia. [further on in discussion] [if] they've diagnosed it, would it save them, because you could put the results in straightaway rather than faffing about with lots of things that didn't work.*

Imogen's account places the activities of the parents in this study in wider context, of how local policy shapes school and teacher options, and the resultant requirements of agency

for a parent. In contrast, for the rural primary school their locality did acknowledge dyslexia-SpLD as a diagnosis and provided school level training and empowerment, **“because we’ve had dyslexia training and they said the diagnosis tends to be up the school for it”** and **“So, say for example with county support, we’ve had training”**. The lack of uniformity therefore means parents may need to show variable levels of agency in different localities and committing resources to secure the supports perceived required.

Parental costs and risk

It was also true that circumstances could change and provision that has been put in place by parents which was filling in gaps left by school may need to suddenly cease or be modified. Some of the parents interviewed referred to limitations of financial, and time resources as Tracy noted when she spoke on an individual basis with me:

TRACY: *but I’m just doing it at home. I mean I come here on a Saturday, he gets an hour’s one to one and half hour on the computer. I pay for him to have private swimming lessons because that’s the only sport and to develop that, a physical and then I pay for him to have half an hour’s maths tuition but that’s as much as my salary can, that’s all we can manage.*

This was like Oliver a substantial commitment from Tracy’s available resources, which included time and financial commitment to provide support to a child. While parents of typically developing children may choose to enhance their child’s educational and lifeworld opportunities, through devolving resources to optimising education; this is a different scenario of necessity. Parents provide an educational stream addressing core needs and core skills because a school has gaps in its assessment and provision, so parents’ perceptions were a child’s needs had not been defined, described, and addressed. However, the parental provision was fragile, freestanding from the school and so not integrated or reinforced. This left it liable to disruption if circumstances changed as happened to Yvette:

I: is she still doing the [support teaching] stuff now?

YVETTE: No, we don't do it anymore.

I: Is that what made you stop is that she wasn't getting anywhere?

YVETTE: Two things, one on financial grounds because we had to pay for it which is a lot, and also I find it, I don't tell people at school this, but I have chronic fatigue and I just find it too much to then at the weekend be rushing around and having to do it.

So Yasmin had two aspects that created disadvantage for her and increased risk to long term social inclusion, the first was that she did not communicate overt distress, thus reduction in motivating parents to action, and secondly resources both financial and personal support to meet her need had become constrained and so were not allocated towards her.

Time as a constraint on effective agency

In chapter 6 (Discontinuity-Disjuncture) there was a comment made by Fraser, a mid-experienced teacher, about how there was only so many hours in the day, implicitly the progress/standards of education he had to meet were beyond what could be managed comfortably in his setting. The counterpoint was that parents, particularly working mothers, who were well represented in this study also had significant daily time commitments.

Vera: I think that there's an assumption that parents have the time to (a) do the reading every day, do this, do that, and there's a lot of loading on the parents to do all of this, whereas in fact we don't have that time.

I: Yes. What are your thoughts about it?

Wendy: Exactly the same, the guidance says I need to do half an hour of homework plus now learn five words every night which is totally impossible, which I complained about, we don't get back until 6 o'clock, which is unfair.

I: And he's tired presumably.

Wendy: So, we do it all at the weekend

What Wendy was alluding to is the way school demands intrude into finely balanced home life. Without necessarily realising it, she is capturing that her child's difficulties are such that this demand, particularly the learning of new words (which would be straightforward for a typically developing child) is already taxing her and redefining the family social space ("**So, we do it all at the weekend**"). Those were the hidden costs of the difficulty but also that the costs to be paid were distributed in the family. Complying with the school and also providing an out of school education stream through external tutoring were also part of the time costs accrued.

The other form of time costs was referenced by Imogen, the lack of efficiency in delivery of intervention that could mitigate against consequential difficulties and damage. Karen worked hard to secure an assessment as previously described, here she describes the outcome:

KAREN; The Educational Psychologist was brilliant, I nearly cried. You will probably be having me crying here [...] she helped because she talked about specific things that he could do.

The costs to Karen's ongoing psychological state and of the load are captured in her comment "**I nearly cried**". However, the information she presented suggested that Kevin had high scores in nonverbal reasoning, "**she had done these puzzles and he was really good at doing those**" and marked deficits in literacy "**she talked about that sort of disparity**". The differences between potential capacity and skills in certain domains was important to move past undocumented parental intuition and internal understanding, and into the world of dyslexia-SpLD being a documented object through assessment process and reporting. In other words to make it visible. To the extent that the assessment was organised by the school she was correct they could not reject the object of the report, but that success was tempered with recognition that the school had delayed matters until Kevin was due to leave. They preserved

the non-visibility and therefore perceived responsibility. Nevertheless, the information stood for the next school. However, as she was later to realise that lost time of efficient education had much more severe consequences **“And now, they have just done some reading and he is at a reading age of eight and he is thirteen”**, ones she could not undo but had little insight around previously.

Child costs and risks

With respect to question II the significant driver for action was child distress, notably but not exclusively at primary level, which was an emergent property from the poor-quality fit of their cognitive and skills profile and the challenges of the environment. Distress was seemingly independent of progress and attainment in driving parental agency. At senior school level, the way in which skills had compromised access to learning became an important focus, notably when parents became aware of the time limited nature of education and the importance of exams to future opportunities as observed above by Karen.

Each of the forms of agency had attendant costs. Some explicit in terms of time and resources, as well as courage and confidence to apply, other hidden in terms of how access to support in a timely way or failure to make sufficient progress had future impact on capacity to engage. However, the main costs were borne by the child who's one-time access to statutory education was being compromised. Perhaps the most challenging account as a researcher was to listen to Tracy's account of Thomas (who was a child from the other evidence with academic potential) and his lived experience at that point of interview.

TRACY: *I don't know because it's just a gut feeling, he's doing letters and sound through the beat dyslexia but he's been asked to critically analyse, he's doing the boy in the striped pyjamas and it's so much more advanced than just reading, you just think the gap is just getting bigger and bigger so maybe we need to say okay, stop, just learn how to read a book and critically analyse it so we're going to try that for a bit.*

I: *Can he actually read?*

TRACY: *He can read but he can read at the age of about a 6 year old.*

I: So he's not even up to reading the boy in the striped pyjamas?

TRACY: *No, he certainly can't critically analyse it, he can't do anything to do with things like images and things like that it's way beyond him, he can't do it.*

Tracy as will be recalled was expressing high levels of agency but had not engaged in much of the forthright form, instead providing as much outside of school she could. The cost for both her and Thomas in terms of his future outcomes was extraordinarily high.

Parents were not always aware of those costs until they became evident as the end point of education came into view, and regret or alarm could follow. That was exemplified by Diane's quote as she reflected on the end of Dave's school education:

DIANE: *I just wish I'd done it sooner, and I just seem to have always been full of regret with Dave. I just always think, 'I wish I'd done this sooner'. The lady said to me, 'I could have done with having him a year ago'.*

The difficulty almost all the parents ran into was that unless they had older typically developing children, they had no other knowledge of the system and what was needed to be in place by what stage and how their child was functioning relative to peers. They also did not realise the uneven nature of developmental processes and the way biology and environment shaped them (Diamond, 2009). It was possible to see from the accounts how the level of function for children in Year 2 set their trajectory, and that it took radical work, pre-emptive action and insight to change that pathway.

Implications for Inclusion

Across the chapter different dimensions of agency have been described and examined.

The research questions were:

- I. What forms of agency are enacted by parents to try and secure good outcomes for the child through access to education and long-term inclusive education?
- II. Under what circumstances, are the different forms of parental agency enacted or not, and what are the consequences of exercising agency or not?

The novel findings in this research are linked to the different forms of agency engaged by parents but also how those forms of agency were linked to different outcomes with respect to inclusion. Drawing from the data, three different novel forms of agency were identified - compliant, subversive, and forthright. Parents overall, but not without exception, tended to use them progressively as a hierarchy; when they encountered resistance from the school or local authority or observed their child having difficulties with educational access and progress, notably with literacy. The subversive form of agency was used to navigate a pathway for skills learning and repair or modification of risk to emotional wellbeing, but without seeking to disrupt the balance of relationships and structure. Within the forthright category that could present as persistence or ultimately direct challenge, associated with state of disjuncture. Whichever form taken they had to self-identify and self-educate, but there was also a pattern of returning to lower levels of agency if opportunity arose.

Considering the data across previous chapters as well as the current one, a theme of parents maintaining engagement but also taking an outsider stance with the school was persistent. That however was for parents who had engaged. As Imogen indicated in this chapter and Frank and Fraser in the previous chapters referenced, parental engagement in their socio-economically challenged areas and the provision of support outside of school could be the exception rather than the norm. This was consistent with the literature (Ellis & Rowe,

2020; Snowling & Hulme, 2020). The implication of that was the entrenchment of progress and attainment difficulties. However, it is salient to point out that it was not individual economic status that determined engagement, the parental case study had a broad array of socioeconomic, social and health profiles, they all had engaged with their child's education. Underpinning much of their activity was a drive to seek to support their child's sense of inclusion with their peers, to be able to fit in and an understanding that education was important in some way.

With respect to inclusion the pattern was that school had variable capacity to identify and meet need ensuring that a child-maintained parity with their peers or met their potential. Under those circumstances parental agency was an important mediator of outcomes and depending upon the level of agency the support that shaped inclusion varied. Of the agency styles, forthright appeared to secure better levels of meeting need in the data of this study, but that required parental drivers, confidence, and capacity to engage as well as forms of knowledge. However, in engaging in either subversive or forthright agency, and the facilitation resulting support, the child and parent(s) had different experiences from the peers. That aspect will be explored in the next chapter.

Chapter 8: General Discussion - The Illusion of Inclusion

She said she was then labelled as a "vexatious parent" for challenging the school.

"People talk about inclusion as if it's a really healthy thing," Gemma said.

"But what inclusion means is trying to make children who struggle to fit in, fit in.

"It doesn't necessarily mean providing what they need," she said.

Figure 24 BBC news report 24th March 2021 (<https://www.bbc.co.uk/news/uk-england-56255272>)

Introduction

The research questions this thesis has explored is how parents of children with dyslexia-SpLD perceive, understand, and enact inclusion. In other words what did parents see; how did they make sense of it, and what did they do about it. The four previous results chapters illustrated, through a variety of descriptions, the perspectives and understandings gathered. They enabled a novel description of the structure of education constructed from the parent and school staff data, positioned/anchored by the child as the central fulcrum through which the structure operated. The novel expression of the structure made use of the parental perspective which had been largely overlooked in prior research. It provided important structural information and context for an unacknowledged gap in the literature and in practice. It also enabled identification from the data of how visibility of differences, and the related qualities of distress linked to dyslexia-SpLD are enabled and are consistent with experiential accounts in the literature spanning over 50 years. At the heart of the ongoing issue is that for a group of children, including those with dyslexia-SpLD they go to school and they become distressed and disabled, school as a space is not inductive to health and wellbeing

The link between this work and ecological literature

In different ways Bronfenbrenner's bioecological systems theory (Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Evans, 2000; Shelton, 2019) and the biopsychosocial theory articulated by Engel (Borrell-Carrió et al., 2004) could be understood as constructing the person in space and that they are also integral to the space they are located in (Downes, 2021). Both theoretical framings of the person contrasted to prior formulations of individuals as relatively closed systems, by their privileging the spatial elements in their descriptions. With respect to inclusion, as a construct and practice it is fundamentally contingent upon spatial features, the permeability of the individual, the context, as well as group membership are essential elements; so, such theoretical frames are of relevance.

Across the literature and results chapters considered so far, different forms of evidence were found to be consistent with both ecological oriented theoretical positions, and broadly supportive of their narrative. However, almost any retrospective account could be accommodated in the models, so it lacked predictive explanatory power, that facilitated future action.

Novel contributions

The novel contributions of this study were identified through application of the critical realism orientation to the formation of knowledge and deconstructing the observed realities of the empirical world into the actual and real levels, which drive those observations through interactions of structure and agency.

This study contrasts with Bronfenbrenner's bioecological systems models and Engel's biopsychosocial one (Borrell-Carrió et al., 2004; Bronfenbrenner & Ceci, 1994). The spatial aspects of Bronfenbrenner's early model do not accord with the structure of the Arc of Education and challenges some of assumptions particularly around their nested spatial and interactive qualities, the data in this study supporting a closer more dynamic set of spatial and

consequential links. For Engel's model this study moved it from the general to the specific in relation to disturbances of function and agency and how they interact to impact on health status of children and families. In part the relevance of Engel's work is the reconceptualization of reading as a whole body-personal and environmental activity, away from the detached cognitive closed system formulations that have had dominant presence in the literature. This is novel framing driven from the data. Where the work in this study does accord with both theories is the salience of environment both at a specific point and the impact of events over the longer term at the individual level. This is exemplified when considering the role of emotion and emotional stress responses both generated by and response to the activity of learning to read and write. The impact moves learning from a pure cognitive enterprise to a whole person and environmental phenomena; acknowledging complexity of the skill both in the immediate, in its impact over time on learning process, and longer term on the sense of self, competency and agency (page 33). These points were initially raised in the literature both as they related to typical pupils and those with dyslexia-SpLD review and explicitly explored as part of the data findings

Both theoretical models suggest how impact of events can be distal, and in some cases considerably displaced and this accords very much with the findings in this study and the literature. The set of findings in this study does demonstrate the value of building a model from the empirical data, rather than trying to fit it into another model and thereby losing important relevant detail. For both Bronfenbrenner and Engel work it was the absence of a strong role of agency in their models that links to the differences in findings.

Further novel contributions were identified through application of the critical realism orientation to the formation of knowledge and deconstructing the observed realities of the empirical world into the actual and real levels, which drive those observations through interactions of structure and agency and formulating a new model of education. This enabled

identification of how three different levels of discontinuity affecting information processing and educational access, lead a child to be 'closer to the edge of failure' and the contingent raising of stress levels which could lead to rupture of education.

Another original contribution was the way in which parents' different forms of agency could be portioned and described (compliant, subversive, and forthright). This flexed around their perceptions of observed realities. It led to different levels of efficacy of interventions that had lesser or greater chance of facilitating inclusion from different perspectives. In this, the final combined analysis and discussion chapter, the literature review, the findings, and the reflections, are considered alongside each other to draw together an account of inclusion that answers the research question and points to areas for future development.

The remaining portion of this and the next chapter will explore inclusion as it related to the research question. How it moved from an intellectual abstract of being a good idea, to being operationalised, shaping the child-parent lifeworld, health, and wellbeing; through capturing relevant reflections of parents and school staff, who in different ways are part of the system. In doing so it drew from the broad ideas of Bronfenbrenner (1994; 2000) and Engel (Borrell-Carrió et al., 2004), as well as Diamond (2009), presenting a dynamic ecological description of dyslexia-SpLD. This included, driven from the data, the innovative structure-agency framework that would allow for future inquiry and to answer the research question while pointing to areas for future re-development.

Universal education: unfulfilled expectations

Across the study data reported in the results chapters, inclusion is an expectation of parents sending their children who have dyslexia-SpLD into school. In the previous chapters several common themes can be detected. Firstly, they have the reasonable assumption that their child should access education, and the child (and parents) be equal partners with their respective peers, both within the community of school and outside school. Parents envisage

their school's tolerance, support, expert knowledge, and accommodation. They anticipate their child will secure the fruits of education that will enable them to move forward in life. There is also an understanding of a form of partnership. Children have an expectation that they will acquire the skills commensurate with their peers.

These expectations are observed as both direct comments and shadows around unfulfilled assumptions and consequences, as they appear in the material covered in the previous results chapters and data more broadly. These expectations are also observed in the literature, where similar accounts of frustration and distress were found, which contrasted with the reports where an inclusive practice was delivered. The expectation by both parents and children of universal access to education has not been directly addressed in the dyslexia-SpLD literature, but has long formed the background to education provision in England (Levin, 2010) and of inclusion itself.

In the data, where provision of universal access was frustrated, and parents or children were not able to function as expected, it was observed to undermine their confidence and trust in the school, in themselves as a family, and in the system. For children at primary level there is evidence in the data that they mostly internalise the problems they perceive and assume that they are the ones responsible. The notion of trust is a key component; in this respect there is a link in the literature that identified the importance of trust to inclusion. Lack of confidence and trust weakened the parents' school relationship and was evident in the data. This was a feature picked up by Lake and Billingsley (2000) in their exploration of conflict resolution, as discussed in the literature review, and the data in the study. This chapter examines these issues.

The key sub research questions the chapter seeks to address are:

- How does general social and educational policy of inclusion give rise to disabling inclusion for children with dyslexia-SpLD?

- What are the differences between enabling inclusion and disabling inclusion: for a child with dyslexia-SpLD, their parents and school staff?

School and parents' expectations of universal education & inclusion

The role and pattern of distress

Starting with chapter 5 (Visibility) and then chapter 6 (Discontinuity-Disjuncture), and finally chapter 7 (Agency), the dominant narrative woven through the parental accounts is one of distress and difficulty by both parent and child. While it was a persistent theme, it was also the case that it was not unitary, there were mixed presentations. A child could be in distress and changes could occur to improve matters, or they could be happy and then find themselves in difficulty. Further, as the previous chapters have illustrated, both children (and parents) could be happy about aspects of their lives but distressed about other parts. What was apparent, was that the parents and children did not experience universal education access across the span of education and the operationalisation of it through inclusion.

The lack of the use of the term of inclusion in parental accounts: insights

Across the results chapters and particularly chapter 5 (Visibility), there is an expectation by parents of universal education. That is, education open to all, meeting need and free at the point of contact with barriers removed. The term inclusion was never directly referenced or initiated by parents in their discussions, until raised by the researcher. However, parents were describing expectations consistent with the literature of both universal education and the operationalisation of inclusion, to achieve that. While parents were describing the practical barriers to universal education, they did not refer to the philosophical or structural construct of inclusion. Apart from one oblique reference, no mention was made to social or legal rights. This contrasted with the group conversation where teaching assistants at a senior school, who work most closely with children having additional needs, made

repeated reference to rights, for example participant 3: **“Like in the lesson. They have rights to, you know ... like drama, so they can all participate.”**

Parents expect to send their children to school, and for those children to make progress, to have positive social relationships and learning experiences, and so secure the fruits of education. However, as outlined in chapter 4 (Arc of Education), while teaching staff in both the survey and interviews generally, but not always, made positive aspirational commentary about inclusion in education, there was very limited evidence they expected it to be delivered in full. This schism in expectations is the first fault line in inclusion in Ordinary Education (OE). It also provides an explanation of why parents of children with dyslexia-SpLD can go to such efforts to try and enable inclusion experience for their child. Much of the work parents described in the preceding chapters was about trying to secure inclusion for the immediate, mid and longer term. They generally perceived their child was not experiencing inclusion and set about as best as they could to address the causes and sources of the barriers to inclusion. The next section examines the parents’ perspective in more detail.

Parental perspectives on inclusion

Importantly, parents expected access to education to happen in line with peers, not in general but with peers of comparable potential. They expected that if there were problems then the appropriate remediation and accommodation would be put in place as described by Tracy:

TRACY: *Well inclusion should be that regardless of a child’s situation, educational attainment, or disability, they should be given an education that suits their needs and if those needs need to be differentiated then that should be undertaken and if it needs additional help that should be undertaken.*

In the opening section of chapter 5 (Visibility) describing the rural primary school, the account of the teachers and Gemma, the mother of Garry (an 8-year-old child with severe

dyslexia-SpLD), met the threshold of Tracy's description. But that account was atypical across the dataset. Nevertheless, there are salient aspects of how that was achieved that could form part of a pathway to meet the aspirations of Tracy, and many of the parents who participated in this study. Those aspirations were intermittently met across the Arc of Education by individual teachers, and across the chapters there were accounts of teachers understanding a child's needs and adapting provision. What Tracy was describing was an expected consistency and a fair hearing of needs recognition, as she went on immediately after to describe:

TRACY: *But it in practice, I'm afraid that funding means it never happens and it's almost as if, at my school in particular, the SENCO seems to have been employed to bat away any kind of difference or needs and literally make the parent think that she's imagining it*

Tracy was describing how in practice epistemic injustice as described by Byskov (2020) was applied by those in positions of influence refusing to recognise the voice of a knowledgeable other, in this case the parent. Penny and Oliver's group interview extracts below crystallise the repeating themes across both the data of the study, but also the literature where for example in one of a number of similar studies Leitão et al. (2017) describe a parallel set of experiences in Australia. This consistency despite jurisdictions, suggests a fundamental structural problem with education systems, one where the profile of dyslexia-SpLD interacts with the configuration of formal education. In the extracts below, Penny and Oliver in their different ways capture how a school system (described by the novel 'Arc of Education') had embedded in it an institutional speed or rhythm, such as expected rate of progress in learning, periods of time studying, and break times.

In the data and in the extracts below its temporal rhythm and pressure is seen by parents as poor fit for the way a child with dyslexia-SpLD learns. For Penny, Peter's education has been compromised and he was in her view the casualty of inclusion designed for others but not for Peter. Inclusion and education practice were not universal from her viewpoint. In

contrast Oliver takes up the challenge from a different perspective of the perceived relative merits of different disabilities, articulating how hidden disabilities such as dyslexia-SpLD are treated less favourably or discounted within sections of the education service, and the pernicious effect to both child and parent of blaming the child.

PENNY: *Inclusion to me and the way it is with Peter is that they have, the educational system have set down and this is what they've got to be taught, this is the way they've got to be taught and at the age of this they've got to be able to do this, this, this and this. Well, all children are different and they don't all learn at the same rates. So inclusion for me means that it's at the expense of his dyslexia, he isn't getting the teaching he needs and taught the way he needs to be taught in order to reach the same standard as them.*

I: *So actually this idea of inclusion, everybody having the same actually acts as exclusion for your son?*

PENNY: *Yes.*

I: *He's excluded, he's not being included.*

PENNY: *He's not being included because they have to be taught that way.*

SUSAN: *They're always given a classroom assistant.*

OLIVER: *Can I add to that, my wife has to play dumb me down because I've got very animated about it, very frustrated in that if my child had two legs missing and the PE teacher told him to get out and run the 100 metres, we'd be taking them off for discrimination. Yet Oscar and Owen, I hear time and time again, it's always from the sodding English department, "you're not trying hard enough", "you can't read", "you can't this" and you think well yeah he's got dyslexia.*

Penny is describing the general social and educational policy of inclusion, that of groups of children occupying the same physical space and having the same or similar material and resources devolved to them. There is an expectation of shared enterprise and activity and

notions of equitability. Those ideas form the base line of the Göransson and Nilholm (2014) four level hierarchy of inclusion, the presence of the child in the class.

Why inclusion fails for children with dyslexia-SpLD

The challenge Penny raised is that this is not inclusion for Peter and to meet his needs it would be necessary to reformat education as delivered, along with the expectations of progress and skill acquisition. The literature review has highlighted the complexity of the profile, and in the section on dyslexia-SpLD there was a summary of how the focus has been on trying to find an efficient route for resolving impairment. What was also alluded to was how this had not been possible. For all the studies there were groups of children who failed to make the necessary progress. Some interventions worked some of the time for some pupils (Carroll et al., 2016; Hatcher et al., 2006; Snowling et al., 2007; van Rijthoven et al., 2021). Of the children who are the indirect subject of the study from the parental accounts, some of them made some progress, but all were perceived by parents to be underachieving on a broader level, and some such a Tracy's son who was at age eleven, were far adrift of basic skills and access to education.

I: *Can he actually read?*

TRACY: *He can read but he can read at the age of about a 6 year old.*

In the Göransson and Nilholm (2014) model the next levels up after having a presence in the class, were meeting a child's needs, then meeting the needs of all pupils. The problem identified by Penny was that for a teacher to meet Peter's needs it would require him to be placed in a position of privilege, in competition with meeting all the other pupils' needs, while he formed a minority. This latter point: the tension between efficient delivery to the majority at the expense of the minority is explored further on in this chapter. From a pragmatic social justice perspective this was an unresolved tension that had several contributory features illuminated through the results chapters.

This account illustrated one of the limitations and misconstructions in much of the inclusion literature, and is implicit in the Göransson and Nilholm (2014) model. Namely that it is possible to meet the needs of the child, particularly as it pertains to dyslexia-SpLD. The model implicitly expects that the child's needs are circumscribed. Further, discreet adaptations or interventions can be applied to level up the child. For other forms of special educational needs, that could be possible if the impairment need does not fundamentally impact on the basic skills of numeracy or literacy; from the data in this study and the literature, that principle does not generalise well to dyslexia-SpLD. Indeed, the allocation of children to ability groups where the children did not perceive they were like the other members was a form of unintended damage, as demonstrated by Xara who at 6 observed she was in **“the group of the dummies as she says”**.

As will be discussed next, some discrete interventions can be applied within class, but they are potential accommodations not remediation. The focus on interventions as accommodation, gave indications of how teachers interpreted dyslexia-SpLD. The restricted nature of their understanding of the problems linked to dyslexia-SpLD was referenced. Their strategies included use of coloured screens and filters, coloured paper or use of a 'dyslexia' font. These were even promoted by local authority advisors to teachers, as noted by Gwen previously in chapter 5 (Visibility), or by Hara, a senior schoolteacher: **“And we try and differentiate, we have for example, for dyslexic kids, we have the coloured sheet overlays, we have a specific font that we can use that's easier for them to read”**. The problem was that the evidence base for these interventions is limited at best and generally of poor quality (Carroll et al., 2017). These adaptations were found across the teacher interviews and may have benefits for a child experiencing visual stress. Indeed, Frank a senior teacher gave an account of accidentally discovering how the use of blue paper transformed a child's access:

FRANK: *You can't read what he writes because of the spelling. And then he wrote a Christmas card to us on blue paper and everything was spelled correctly. We went wow, maybe its blue paper.*

I: *Did you get a chance to try any of those?*

FRANK: *We decided to trial it this week. And it's simple things like that because we wouldn't have thought about it because we hadn't had the training. It's not the first thing that goes to your head 'oh, I must try him on blue paper'.*

Provision of strategies to deal with visual stress, while they may be of some assistance to those with dual presentation, do not address the core deficits of phonological processing found in many (but not all) pupils with dyslexia-SpLD.

However, the fundamental problem, one not limited to visual stress and alluded to by Frank, was a lack of knowledge about what interventions were a form of longer-term remediation, and when, how and by whom they should be delivered so that they addressed barriers to education. Alternatively, which strategies are those that seek resolve differences on a localised or temporary basis (accommodation) and how can they be successfully used alongside remediation? The selection of intervention strategies, particularly those applied for accommodation had the potential for exacerbating the child's longer term educational deficit on a progressive basis if in each subsequent lesson the strategy was poorly applied and progressive gaps in knowledge and skills were thus opened up.

At the heart of the difficulty is that such accommodation/remedial measures, for example, coloured films are of superficial impact, in that they do not require the teacher to make fundamental changes to content and delivery. In contrast effective teachers, such as the science one Karen described in chapter 6 (Discontinuity-Disjuncture), who did reconfigure his teaching, made an important contribution to Kevin's learning in that subject and his broader

confidence as a pupil. However, for Kevin those skills were only applied in science and with that teacher.

In Beth's case below she described a mixed strategy at Bob's primary school, with the teacher providing access to materials, again focusing on visual interventions, but also addressing short term and working memory limitations **"didn't get Bob to rely on the whiteboard as much"** via differentiation, as well as psychological type support **"it was her demeanour and her caring kind of nature"**:

BETH: I think she kind of gave him, you know, number lines and possibly used to different coloured paper and didn't get Bob to rely on the whiteboard as much, so subtle little things like that, you know, helped him, and I think it was her demeanour and her caring kind of nature

However as soon as Bob changed class teachers, the access to learning stopped.

Such definitions of dyslexia-SpLD as a visual stress issue, which was the common account by teaching staff in the data, impacted upon the children's inclusion. The reality was that the impact of the profile was such that the children reported on (via parents and teachers) in this study were commonly out of time and phase of skill development for accessing education. A key component of this, was the unrecognised and novel finding of the contribution of discontinuity, and its progressive impact creating disjuncture on both educational access and a child's self-perception. Penny's account highlights that built within the broader social and educational policy of inclusion are temporal constraints limiting adaption and accommodation. From the data the common account was that children could have inclusion, but only if they could keep up with the rest of the class.

In contrast Oliver considers how the relative invisibility of the dyslexia-SpLD diagnosis meant that the accommodations that would be provided and sympathetic, a stance that may be expected from visible disabilities and difficulties, were missing from his son's education. He expresses frustration at how there is structural inbuilt institutional tolerance for lesser

provision and social awareness. The notion of blaming a child for their difficulties and disabilities leaves him very cross.

In one form or another the two accounts by Penny and Oliver of poor fit, relative invisibility and poor levels of knowledge, complicit lower aspirations and support, all leading to inappropriate interactions and expectations, thread through all the parental accounts when they describe failures of inclusion. This is an account of incomplete inclusion in which only some children in the class/school have aspects of and access to a perceived form of inclusion. It is inclusion for those who fit into the system. This chapter examines why inclusion is an illusion for children with specific literacy learning difficulties, otherwise known as 'dyslexia', by the parents.

The aspiration of inclusion to dissolve disabling environments

Macdonald's six models

Macdonald (2019) described six models of how dyslexia-SpLD was positioned by research inquiry. Collectively they describe different levels of analysis and ways of understanding difference, disability and disorder, and the degree to which the perceptions of the source of the problem is located within a person, outside the person, between the person and the environment, and how difference is described.

The six constructs are helpful as lenses through which to understand how parents differentially conceptualised their understanding of the observed realities of their child and their experiences. The social model of disability described by Macdonald (2019) generated a useful distinction between impairment, which was located within the individual level, and disability, as a socially constructed phenomena, emerging out of the poor adaptation of the environment to meet needs. Disability in this context is a moveable moment-by-moment state, context-dependent. It has the appearance of permanence due to systems and structures and the perseverance of the impairment.

The relevance of the social model for this area of work lay in identification of the environment as a salient feature worthy of attention and, as illustrated by Penny and Oliver's commentary playing an important mediating role. As described in the literature review, substantial research effort has focused upon the within-person features of cognition and processing. The environmental features have received less research attention, and even less attention has been paid to the nature of the interpersonal factors mediating disability for this group of pupils with dyslexia-SpLD. Moreover, there has been only limited exploration of the impact of dyslexia-SpLD on mental health, and even less over a longitudinal time frame, with Carroll et al. (2005) providing some of the useful insight.

The school environment: the social model

For a school, the physical environment pre-exists and forms its geographical anchor, located physically in community space. However, as discussed in chapter 4 (Arc of Education), how its physical space is structured, used and the cultural practices that operate within it, are under the direction of the staff. The organisation reflects the social context and forces acting on it, which includes the wider national policy. The specific interpretation and expression of this is in the culture and mores at the school level. Across the data parents and children were not typically found to have substantive influence over the school environment, though this did not stop parents or children trying, as the following extract from Nora illustrated.

Nora: Well, we wanted a link, we wanted them to work with her [private specialist teacher] to support the work that she was doing and they wouldn't. So, it was very difficult because they were doing something completely different, they weren't supporting the specialist dyslexic teacher who knew what she was doing, and I thought it was like piggy in the middle, it was just... it was bloody awful really. And we asked and asked them, and we actually showed them stuff saying could you do this with him, because he was taken out of lessons at times for one-to-one interventions, so could you work on this with him, so he got some continuity, and they wouldn't do it. They said that they knew the best... well initially they were going to do some of his work with him there [after school clubs] but I didn't want him to because that was free time to and play. Nathan was a very sociable little boy, as he still is [...]

I: Why did he finish with [private specialist teacher], because he was getting stressed and they weren't actually working cooperatively....

NORA: *He didn't want to go because it was just too much for him. I think everything was just building up and*

Nora's voice was used in both chapters 6 (Discontinuity-Disjuncture) and 7 (Agency), where her experiences contributed to the descriptions and analysis of the impact of both disruptive features in education, and parental efforts and agency, to remediate the challenges observed. Nathan's marked difficulty in acquiring literacy skills and consequential lack of access to education formed the central part of her account and drove her efforts to secure the support he needed. In this respect Nora's efforts captured the common account across all the parental data.

In the above extended extract those elements of discontinuity and agency are both operating and the consequences on her emotional and psychological state are laid out when she described **"and I thought it was like piggy in the middle, it was just... it was bloody awful really"**. However, the impact of the limitations was not limited to literacy, they had broader impact on self-concept and how Nathan and Nora saw he was classified and where he belonged (or did not). Like Xara in the extract previously, in the following extract Nathan is describing the peers he has been linked to

NORA: *he was with in the bottom set, there were a few which he found, some of them funny but they could be quite disruptive. But he said, "You know, they can't help it mum because they're 'special'."*

Nora's two extracts are illustrative of a number of features considered in this chapter. The lack of or poor alignment and discontinuity between school and home offering (for example where Nora describes a level of competition rather than continuity between strategies used), the parent perception of limitations around teacher knowledge and competency in specialist areas, the psychological stressors experienced by parents and the

way the parental knowledge and expertise of their child was not recognised. For the latter it was also the perception that a child of capacity was being written off and having a lesser education (**“they could be quite disruptive”**). This was along with the way school staff responded when the public face of competency was challenged. Each of those points has been raised and described in preceding chapters, but in this chapter, they will be used to describe constructions of inclusion.

The social model and child’s voice: future possibilities

What is not immediately clear from the extract, but is embedded in it, is how while Nora was making decisions, for example **“but I didn’t want him to”**, she was seeking through multiple channels to be Nathan’s voice, and to act on his experience of the world and her understanding of him. She was protective of his social time and social world, and she acceded to Nathan withdrawing from conflicted education focusing on literacy. However, in her main account she is implicitly trying to give voice to his need to make progress, to secure outcomes like his peers and have a future to be proud of that draws on his natural strengths. This was not to focus on academic prizes, but on possibility and pleasure, as she noted **“Nathan wants to be able to run his own business as he says, he thinks very much outside the box, and he would like to be able to teach in outdoor pursuits.”** Which was similar to Rachel’s observation **“his PE is above [ARE], because that’s what he likes you see”**, or Susan’s comment on Sarah her daughter: **“Sarah is really caring, really caring and wants to be everybody’s friend”**. This is a model of inclusion which is less focused about levelling up to peers in the classroom, more about excellence of individuals and future possibilities. It was about describing an alternative sense of self not defined by impairment. In that respect the lens of parents was of neurodiversity as described by Macdonald (2019) drawing on Grant (2012).

Neurodiversity is present when an exceptional degree of variation between neurocognitive processes result in noticeable and unexpected weaknesses in the performance of some everyday tasks when compared

with much higher performances on a subset of measures of verbal and/or visual abilities for a given individual.

(Grant, 2012, p. 35)

What is pertinent in relation to this thesis is how parents seek to draw upon ‘normal accounts’ to position this unusual level of difference when Wendy observed **“I think it’s just making sure everyone can have areas where they can shine. Because everyone is going to have difficult areas.”** This could be inferred to be a repair and resilience strategy, one that suggests that effort from within will be required, and that narratives of deficits could be mitigated. Nevertheless, that did not perhaps recognise the enormity of the impact of weakness and the challenges they posed were well outside the typical range of difficult areas, and perhaps the undervaluing of the contribution of the strengths. This is a very different model of inclusion from the literature, one not about homogeneity but about diversity and excellence.

Parental distress and drivers

Across the literature the accounts offered are consistent with the finding in this study about the levels of difficulty and distress parents bare. This challenge to parental resilience and associated links to poor health of mothers was found in the English longitudinal study by Snowling et al. (2007) through survey, and alluded to in the Leitão et al. (2017) study of 21 Australian parents and 13 of their children, with concerns and focus of parents on the mental health of their children. The findings replicate the observations of (Riddick, 1996, 2010). What is being broadly described in the data of Riddick’s or the present study and also in the literature is how disturbances of broader inclusion for a child with dyslexia-SpLD generate psychological and mental health concerns as observed realities by parents, who then seek through various forms of agency to alleviate or protect their child from distress.

While the parents’ lens is the focus of the present study, the concerns for children’s health and wellbeing were not just the interest of parents. All the teachers interviewed had a

deep commitment to their pupils; they did not all have sufficient knowledge to optimise their help, but their concerns were genuine, and there was plenty of evidence from the parents' accounts reported in the previous chapters that attested to other teachers' efforts.

However, there was also plenty of evidence of teachers and school not understanding and accommodating dyslexia-SpLD, and there was evidence of this too in the school survey. What this meant in practice was that children's experience of education was uneven and so too their experience of inclusion, or lack of, which parents sought to modify. This then also gave rise to another novel finding about how children operated 'closer to the edge of failure'. While typically developing children could and did have the resources to cope with the unevenness of education, the children with dyslexia-SpLD did not, and small changes had marked impact on their progress for good or ill. This was education being negotiated within very narrow parameters, with parents through outside effort, such as Nora, seeking to broaden the space the children could operate in.

The child's voice through the parent

This study has examined the parents' perspective of what their contribution could be in facilitating better outcomes for children with dyslexia-SpLD in education. Through that data collection and analysis, it has illuminated how the social and educational policy of inclusion gives rise to circumstances that can be recognised as generating disablement and disabling inclusion, as articulated by Penny and Oliver. Understanding of the parents' role has evolved through the study, with the data suggesting a new extension of why the parents' role is important and the way certain narratives around dyslexia-SpLD were perceived as harmful.

At its most straightforward, the parents were not just external commentators or observers of education, and the child a voice on the side. They were the channel through which the child had communicated their difficulties and distress, their successes, and their strengths. They as parents were communicating the child's ambition, hope and aspirations,

and the pain in those aspects that had been thwarted. In short, they were providing information about the child's identity. Secondly, they sought to provide more educational and functional resilience in the child and to enact inclusion through creating alternative narratives, creating opportunities and providing bespoke support. The difficulties and distress of the child are at varying levels experienced as embodied by the parent.

An extract that captures this role of parents is Nora's resistance to more after school homework classes, and her preference of the time being used for playtime as it would for any other typically developing child "**because that was free time to play, Nathan was a very sociable little boy, as he still is...**". In this extract she can be seen to be seeking to preserve the notion of the typical and his need to have 'the ordinary' life of peers, if only in selected moments. But to do so she had to take some pressure and experience social and emotional difficulty, in a way other parents without that challenge never have to. It is not only the child who has atypical experiences, so do the parents; perhaps never more so than when they must engage in the legal process, as six of the participants did.

This did not mean however that emotional and psychological experiences and meaning could not be observed; parents made differential use of understanding their child's mental state and the causes of it. For example, Rachel supported her son Robert with alternative narratives: "**they all say to him 'oh you're square'... I say 'just ignore them', 'you want to get on with things, you want to get on with your education, you just don't listen to them'**". The predisposition to anxiety disorders and also depressive ones that Rachel is implying, were identified by Carroll et al. (2005) as linked directly to literacy difficulties. Other wider ranging accounts of distress were given in chapter 5 (Visibility).

Finally, the parent is speaking for the child in terms of their aspirations and hopes, speaking to their potential and the possibilities for a future. So, the muting and ignoring of the

parent is also silencing an important form, the voice of the child; a voice that may, from the data, only be accessible through the parent or guardian.

Child voice

The mixed presentations of how a child's voice was recognised and articulated were found across the parents' case study which included longitudinal, group and individual interviews. They included accounts of distress, happiness, pride and despondency, but the substate was of a desire to identify areas of strength as a compensation for the narrative of difficulty. In the following extract Wendy elaborates on this idea:

WENDY: *so if Wayne has to do a spelling test where he will
get 1 out of 6, then afterwards he should be given a drawing test where
he can 6 out of 6*

In this respect the accounts were consistent with the findings of Snowling et al. (2007) who found that children segmented the impact of dyslexia-SpLD on their self-esteem partitioning the sense of self. Like Snowling, Muter and Carroll's (2007) 10-year study of dyslexia-at-risk families, the longitudinal work in this thesis allowed for participants to capture data over time. However, unlike Snowling et al. (2007), which principally focused upon quantitative data capture as part of its design, the qualitative nature of this study enabled a focus on the perceptions, with both participant's and researcher's capacity to reflect on experiences as part of understanding the drivers below the observed realities. The data in this study though was suggestive that while the children did partition their experiences and had internal discontinuities, the impact of the areas of difficulty were more pervasive than may have been recognised. It was perhaps more evident when a child had a change of environment for the positive such as the accounts by Yvette, Lucy, Diane, and Beth, and a comparison could be made before and after the transition.

At the most obvious, what this highlights is how seemingly similar school offerings in mainstream ordinary education (OE) provide very different access to universal education for

the same child, as Yvette commented after Yves changed school: **“We don’t have battles over things like going to school in the morning, he gets up quite happily and he just trots off, and he’s happy”**. It is therefore unclear why there would be an expectation that universal intervention strategies, some described in the literature review, would produce uniform or universal positive effects or secure consistent inclusion. What the child’s voice contributes is a counter account of how evidence-based practice, or even just custom and practice, is overvalued without the taking of a critical stance. A good example of a critical stance was given by Gwen from the rural primary school, when she reflected on the inappropriate persistent use of phonics past Year 3 **“because it isn’t common for schools to stop them, they do just seem to keep slogging away. Well that poor child.”**

The geographical features of inclusion - how the child occupies two worlds

The geographical qualities of time, space and people create two distinct lifeworld experiences: one located in a school, the other anchored on the home. The structural features of the school include that there is the world of operational visible power relations as well as invisible ones. There is also dissolving of presence of the individual child into a member of a group within the school, as well as school forming a mini and abstracted community world, a place of rehearsal for real life and society. School runs to its own temporal pace, in part driven by outside agencies of policy and shaped by the financial constraints of service availability, something teachers were acutely aware of which was briefly described in chapter 4 (Arc of Education) and parents commented upon.

The second geographical location is the child’s home, one of its own private culture, location, and social structure. It too had financial and resource constraints, but they were specific rather than general. How the child experienced and was observed to experience both locations became an important matter for the parents. It was linked to how they constructed

their understanding and role in relation to their child, particularly when acting as their voice and advocate in the social world of education. For hidden disabilities, the experiences of the child in school may only become evident outside, as articulated in chapter 5 (Visibility).

Chapter 4 (Arc of Education) highlighted how from an education orientation the child is operating in two geographical worlds. Later in life children will turn into adults who will in all probability also operate in two worlds for at least some of the time; but at that stage they will normally be able to exert agency around those choices. This is not the case for the child who has very constrained agency and where the worlds both have important roles in shaping their sense of being. For the child with dyslexia-SpLD, the school environment contains many of the sources of distress and difficulty, and some of the opportunities to shine, but the balance is not equitable. This can rapidly develop into levels of stress and avoidance, for instance Gemma **“He didn’t like coming in [to school]”**. The child’s way of being, and understanding the shared world, culture, and business of being in each geographical space became an important aspect of the parental accounts, particularly as it linked to perceptions of distress and difficulty. These are accounts of children being placed in situations on a daily basis of persistent trauma.

Previously the temporal nature of the school space was highlighted. The lifeworld experiences of schools are evolutionary but generate discontinuities and disjuncture’s for a child. With each successive academic year and phase of education the aspirations change along with demands and age-related expectations, sometimes with marked disconnectedness. In contrast the home space is one of gradual developmental change in which parents compensate and adapt. An example was Lucy’s management of Larry who was 14 at the time, and she had observed his younger sister age 11 did not have the same problems:

LUCY: Because I always try and give him routines like I’ll say to him your uniform’s always in the same place so make sure it goes back there, put your tie in your blazer pocket, it’s always going to be there and you’re not going to lose it, and make sure your shoes are in the cupboard because then they’re always going to be there, and if you can check not

every night but every other night that your pencil case is fully loaded with everything you need for the next day you're ready to go mate. Without me saying that it never gets done, not even pick your coat up.

Larry's experience of education was not positive, so it is possible to also understand this as behaviour expressing feelings around disengagement from school as well as developmental difficulties. Irrespective of the drivers of the behaviour, it was something Lucy was supporting to reduce the potential of negative responses in the school setting. This was work at home to enable a minimal form of inclusion rather than naturally allowing exclusion in the school setting to occur.

Location differences and shared and non-shared space

Each of the parents spontaneously gave a longitudinal story, tracking through their ups and downs and decisions. In contrast to the school, the rate and type of development in the home has a natural pacing set within the family and save for exceptional unforeseen circumstances, this from the data differed from the education pacing and expectations. Sometimes it was in specific ways, for example more advanced, such as Yvette describing Yves age 11: ***"he's really, really into current affairs and things like that, so he'll listen to the BBC World Service when he's going to bed at night"***. Sometimes children were further behind, such as Rachel's account: ***"Robert doesn't like reading at all and will not open a book"***.

The importance of discontinuity facilitating risk to education and inclusion was explored in chapter 6 (Discontinuity-Disjuncture). A rare example of attempts at bridging the physical divide and dealing with discontinuity outside of the school location was given by Imogen, a SENCO for a primary school covering an economically and socially challenged area:

IMOGEN: some families and parents that are brilliant, want to speak to you, want to be involved, want to read the paperwork, attend meetings, and you have some that never respond, never come to a meeting, not there when you go out to their house.

From this it is also possible to see how there could be resistance by parents in some of the hard-to-reach communities, to engagement with a significant government system structure. This aspect was raised in the literature: for example Macdonald (2012) is one of the rare researchers whose studies have addressed difficult to reach communities. However, the reluctance to engage could also be by the school. When Parent 15 was looking around for a secondary school for her child, she found that getting over the threshold could be of itself a challenge:

Parent 15: *[...] the SENCO was so determined not to have a discussion with me, she basically ran ahead down the corridor and in front of me, and I couldn't catch her. I literally couldn't catch the woman.*

I: I'm sorry to laugh at that, but the vision of this woman running and you running after her, it's just -

Parent 15: *And in high heels. It was quite impressive.*

So, the construct of inclusion presupposes that there is mutual territory to be shared by parents, school and child. In this respect the study deals with those parents and families who do share aspects of a common space, and the way that space was navigated. When there was not shared space, such as rupture in school relations/capacity to meet need, then new spaces had to be identified such as in the cases of Nora, Yvette and Lucy. Alternatively children may disengage within the space as in the case of Wayne, who having been humiliated when he was not able to read his own work for a position on school council in front of the class, his mother reported: **"I don't think he will go for it this year because of that, because he wrote it and realised when he stood up he couldn't read it."** Similarly, Vera reported on seeing the task demands: **"Vince wanted to go up for school council but as soon as he realised he had to write a statement, he said no"**. In these cases, inclusion had failed. The children were aged eight and nine.

Core themes of inclusion

At a very simple level it is possible to crudely measure the efficacy of inclusive practice at the end of education, by comparing the education outcomes of children with Specific Learning Disabilities (SpLD) with those who do not display having them. What is evident from the 2020 government data (Gov.UK, 2020b) is that the children with SpLD are only half as likely to achieve maths and English at a grade 4 level (basic pass) as their non-dyslexic/SEN peers (35% vs 71%), and only 18% will make grades 5-9 (good pass) compared to 49% of the non-disabled peers. With respect to the quality of general qualification achieved across the expected range of a balanced curriculum, the children with SpLD secure 34.4 points (a notional average of grade 3.4 per qualification), while non-SpLD secure 49.9, a notional average of 4.9. The SpLD group, on average, fall below the threshold (of grade 4) for each GCSE and a wide range of post-16 options, while the non-SpLD group have a broad and fuller range open, as their average is above 4 and almost grade 5 for each GCSE. If a marker for inclusion is that children are well positioned at the end of their education, that is to enter society on an equal footing to their peers, and achieve their potential for contribution and participation, health and wellbeing, then these results indicate this has not happened.

This section looks at the contested space of how inclusion was perceived. A number of pertinent themes occurred across the data and two of the most prominent of these will be described below. They address how a child's voice is central to inclusion, and what happens when parents perceive a lack of visibility and inclusion. There have been multiple accounts describing or seeking to describe both children with dyslexia-SpLD, and their family's experiences that remain consistent across time and have not fundamentally changed. What has not been directly addressed but implicitly drives the accounts, is the lack of inclusion, and therefore the lack of access to universal education. While literacy forms a central role not only in education but mediating much of social, economic, and democratic activity, it is the capacity

to be visible that frames inclusion. Inclusion presupposes that persons become visible. The silencing of voice, particularly a child's voice, is the antithesis of inclusion.

Circumstances that caused parents to challenge provision offered

One of the questions from the phase one data capture for the longitudinal group was: What had prompted them to take action and challenge the provision they had been offered so that different provision was available for secondary school? In the three extracts below (all three have been anonymised) different dimensions of why parents acted are captured.

Parent 1:

but if you are a parent who is saying well actually my child is bright, they are smart, they have all these impediments to work with but they are still smart and they are still bright, they still learn, they still need incentives, they know they are smart and actually if you keep treating them as thick they are going to become demoralised

Parent 2:

Because he wasn't thriving.

I: Right OK. In a nutshell describe to me what not thriving meant

He was still struggling with his reading, he was struggling with his Maths ... he didn't want to read. His writing was dreadful, he couldn't write a proper sentence, the spelling was atrocious.

I: So, this was basically a long, long list of where he is just failing to meet the basics?

Sure and self-esteem was like...pants

Parent 3:

And what really terrified me was that fact that, as [...] getting older, [...] beginning to understand about how you can really kill yourself, you hear all these [...] terrible stories in the paper.

While across the data parents were focused upon the degree of fit of the child to the school system, in the extracts above they collectively as well as individually, were also describing the risk to the child's long-term health, wellbeing and child's voice and aspirations. So, the focus on fit in the immediate time frame, was within the context of outcomes across the span of the Arc of Education and beyond. They were describing barriers to inclusion. For parent 1, it was low aspirations and not meeting need; for parent 2, it was fundamental skills needed to access and succeed with qualifications and future opportunities; and for parent 3 it was the fear of life limitation. The parents were prioritising the emotional lifeworld of their children, how the world would likely look to them, and then sought to act on those aspects they saw that placed them at risk. They became their advocate and voice about what was needed to ensure inclusion, not just within the context of class or phase of education, but beyond and over their future lifespan.

Parent perceptions of child inner world: other accounts

The perceptions and understanding of the child's inner world by parents was also described through the observed realities of events. Discussions across the data included how children experienced 'othering' in school and social settings; this included bullying, which appeared in a number but not all of the parents' accounts. Some accounts were transitory and location specific such as name-calling and identity labelling, illustrated by Rachel's son. Other times, peer group cruelty and rejection as described by Tracy: **"he's described instances where a whole group of kids playing football with him would chant off, off, off until he came off crying and stuff like that"**, was more impactful and destructive. At the extreme end of a child's internalisation of distress was an account of expressions of wanting to die, and also of avoidance of school, for instance example in Parent 10's accounts at the end of chapter 5 (Visibility).

The more typical account was disengagement and behavioural manifestations such as Vince and Wayne previously in their school council applications, or such as disrupting a class by Kevin in the science lesson. An extreme form of disengagement through physical aggression, for example the chair throwing of Larry in Lucy's account, demonstrated there was a spectrum of responses by children reflecting their own history. Both Kevin and Larry's experiences are captured in chapter 6 (Discontinuity-Disjuncture).

Despite the visibility of distress within school for Larry and Kevin, the source for much of the child's voice was from within the private space of the home and the child's accounts of how being in school was for them. For Wayne and Vince, it was in the home they expressed their hurt, Wendy describing **"he came home and sobbed"**. Presentation varied, but they were all different forms of behavioural communication. Some such as somatic complaints and manifestations were persistent and frustrating for parents, captured by Yvette's **"I mean we used to constantly get 'I don't feel well, I've got tummy ache, I can't go,' blah-blah-blah-blah"**, or Parent 10's child school related distress **"So he'd often wake up on a Sunday night and be violently sick in the middle of the night, or be inconsolable, wouldn't stop crying and shaking, couldn't speak"** etc. provided a notionally valid (medical) reason not to be in school, as well as an expression of stress. Alternatively, some forms of child communication were difficult because they were only expressed in the home. This increased the difficulty of parents getting a hearing by the school, for example Susan's experiences of Sarah's tantrums **"she had some terrible temper tantrums at home but was really good at school"**, or Karen's experiences of Kevin **"and his behaviour at home was awful as in tantrums, throwing himself on the floor, storming off and I've had to really work at that and be patient"**.

Across the geographies of school and community, children transported their experiences with them. When the school space crossed into the home such as through

homework, this was frequently linked to distress. The imposition of homework meant that child was not able to partition the worlds.

Summary: suffering playing an outsized role in accounts of dyslexia-SpLD

In the literature the focus for inclusion is on the class and the school (Göransson & Nilholm, 2014; Nilholm & Göransson, 2017) and the driver is principally about levelling up. In the forms of inclusion described, inclusion is done to the child by adults or peers. That perception of how inclusion is operated was the one that dominated the accounts by teachers. It was also the nominal account given by parents when they were specifically asked. However, theirs was slightly more nuanced. Beth concluded **“To be honest, inclusion in a class of 30 is not actually possible”**.

Little attention has been paid in the literature to how inclusion poorly operated can be a source of trauma or that the geographical limit of inclusion is not the school, both of which have been identified in this study. Importantly the accounts are about adults doing, not about the child voice and presence. This is a study of how a specific literacy learning difficulty, referenced as dyslexia-SpLD, shaped inclusion, but the account is one in which suffering plays an outsize role, manifested as sustained psychological and emotional duress. This pain was linked to immediate sources of threat to self or self-identity; or to longer term hope and aspiration linked to self-expectations of social roles, as Yvette described: **“later on in the school he got a lot of bullying for his dyslexia, there was one child in particular he was like you’re so stupid, you’ll only ever be a postman when you’re grown up, things like that”**.

The parents’ distress was in response to their child’s expression of experiences and meaning-making in their daily life as a learner, and as a social being within the education system. However, the distress, anxiety and anger/frustration parents articulated was also in part due to their inability or difficulty in being able to have their child’s voice heard, as

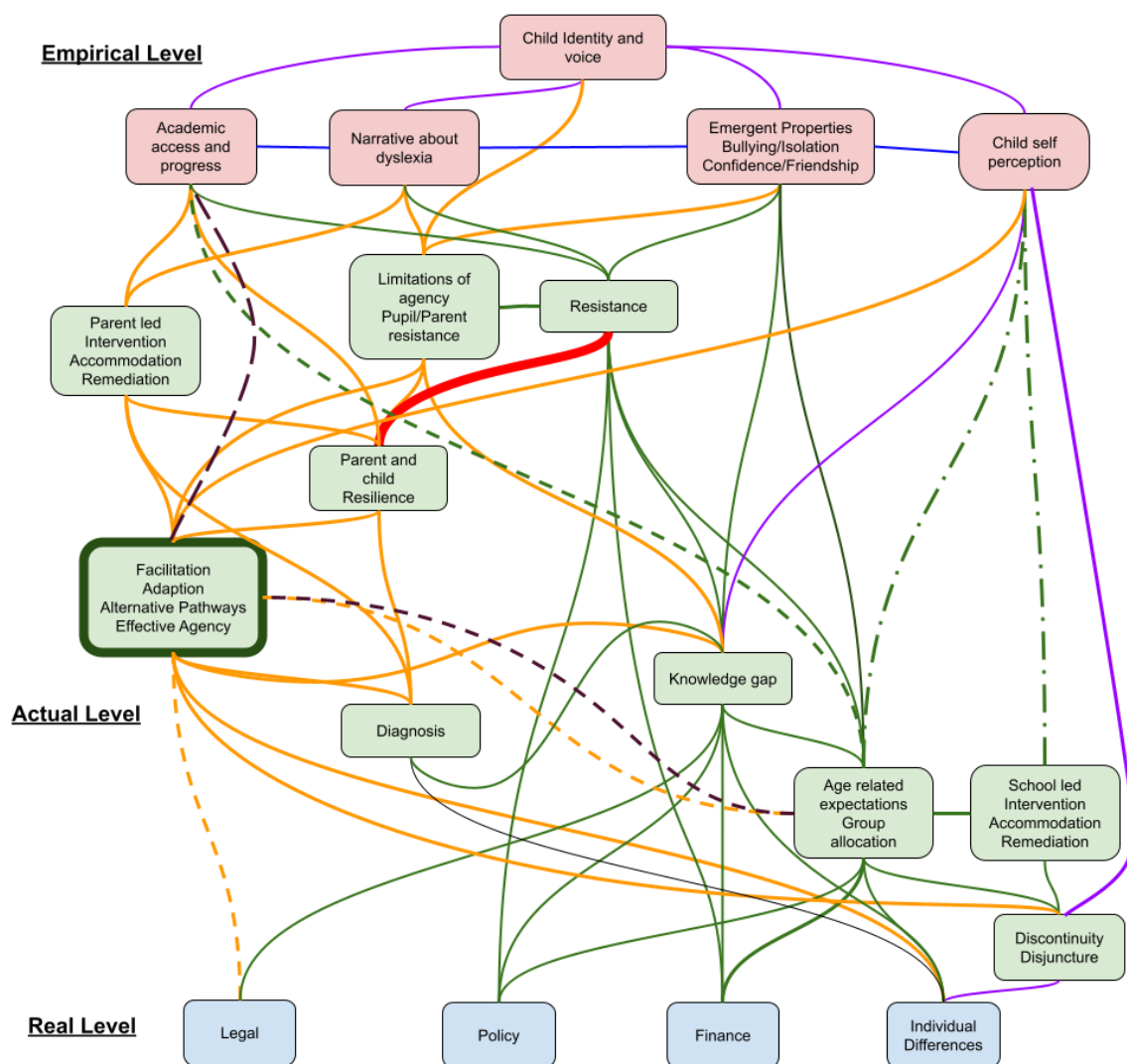
represented by themselves and by those with authority to act. This was epistemic injustice (Byskov, 2020). Their frustration was anchored in the reality of their lack of efficacy and being ignored as a source of relevant authority. Tracy spoke for many when she said:

TRACY: *Well they, yeah I mean I'm so embittered by the entire education system that I don't, my expectations have just gone through the floor, I just think that's the most we can hope for now*

These findings are not fundamentally new, they represent a consistent account of parental experience, one to date that has been ignored. What is new is the linking of the parental account with the rendering mute the child voice and why and how that child's voice is central to the development of inclusion and mitigation of educational and wellbeing inequality.

Critical Realism as a structure to explore inclusion and child voice and identity

Across the three levels of the critical realism architecture of real, actual, and empirical, a range of evidence supports factors that shape the perceptions, understanding and enactment of inclusion by parents for their child. As Leitão et al. (2017) note in their study, the principal driver for parents is that their child accesses fundamental education and fits in with their peers (Lithari, 2019). This section examines how four structural features at the real level generate a wide range of perceptions, understanding and actions by school staff, others, parents, and the child at the actual level. This is then mediated by the types of agency by parents, and the degree and type of disruption of discontinuity-disjuncture, which result in the observed realities at the empirical level. Those realities are expressed as the narrative of difference, academic access /fruits of education and degree of social acceptance engagement creating the child self-identity and voice. The interrelationship of the core components is graphically represented below.



| | |
|---|--|
| Real | Real level |
| Actual | Actual level Principal site of inclusion |
| Empirical | The observed realities of the Empirical level |
| ————— | School led pathways |
| - - - - - | Expected or hoped for observed realities of school led intervention |
| - . - . - | Alternative observed realities of school led intervention |
| ————— | Parent led pathways or parents working in partnership with school staff and others |
| - - - - - | Sources of knowledge and influence for some, but not all parents |
| ————— | The impact of discontinuities and disjuncture - bidirectional |
| ————— | Major point of conflict through the different levels of agency |
| - - - - - | Individual teacher agency and facilitation |

Figure 25 Graphical representation of the Discontinuity & Disjuncture pathways derived from parental and school case study data

Features of discontinuity & disjuncture and their role in inclusion

The above graphic is an abstracted summary derived from the data of how parents perceived and understood educational inclusion and its enactment. The graphic has two principle sets of pathways marked, those led by school (green) and those by parents (gold). These are paths of agency engaging with structure. The graphic captures the degree to which the forms of agency had only limited interaction. For some areas such as diagnosis (the detailed account, not just the label), the information was valued by parents, but from parents and schools' accounts not engaged with by many of the schools, though that was not always the school's choice. While many of the features in the graphic have been identified in the literature up to now (some are an active source of debate such as diagnosis (Gibbs & Elliott, 2020) as highlighted in the literature review), they have not been schematised.

The graphic also has some lines of direct influence notably from the disjuncture unit. There was also horizontal bidirectional interconnectivity at the shoulder between the actual and empirical levels. The red line was explicitly about agency, the pathway between parent resilience and school-system resistance. This had been the source of much of the academic focus of parent focused research (Leitão et al., 2017; Livingston et al., 2018; Riddick, 2000, 2010) and the contested space as described by Kirby (2018). The novel contribution was to understand not only did parents have engagement but they used different mechanisms of agency, and those produced different outcomes towards different forms of inclusion across the Arc of Education.

The graphic when broadly considered has an upwards pressure from the real to the empirical. However, at the actual level, while the general trajectory is represented by things doing the influencing having the connection from the top of the box to those being influenced having the connection at the base, the traffic is two way. For instance, limitations in parent and child agency may lead back down to alternative pathways. These may in turn lead down to diagnosis, and draw from individual differences, knowledge, and then back up again to

effective agency and resilience, and onwards. Those pathways were explicitly found in the data, as were the general multidirectional aspects. The actual level is characterised by its dynamic qualities. Those parental perceptions were clarified through the use of the teacher accounts and data, identifying common ground and what were points of departure or partial perceptions.

Summary of the findings applied to the Critical Realism framework

Across the data the four identified structural features at the real level generated around thirty-three identifiable new structural features that were shaped by agency or interactions between agency and structure. For ease of processing these were consolidated into thirteen, and then further consolidated with others sharing similar features into nine groups, plus four that bridged the actual and empirical levels. These structural features were mediated by the type and nature of disruption in the form of discontinuity-disjuncture at its three levels: micro, meso, and macro, and the type and nature of agency by the parent or school staff, and the degree of persistence and resilience linked to that.

From this graphic it will be seen that of the four components at the real level, only one directly informs all parents: the Individual Differences. Only some parents are informed by the legal framework structure on the graphic represented by the gold dotted line. Parents are limited in their use of the policy and financial frameworks information, and it seemingly was only partially available. It was generally not seen as open to either direct challenge or the interpretation of it.

In contrast the school is principally informed by policy and finance frameworks, as was tracked through the results chapters, many of which were perceived to draw from upper levels such as the local authority. For instance, not to diagnose dyslexia-SpLD, as Imogen referenced: **“I would assume that’s because it’s not diagnosed locally”** or Fraser referencing national policy: **“What we struggle with massively at this school are those standards in reading and**

writing and maths”. The school’s focus was on broad individual differences that spoke directly to the practice of teaching as discussed in the previous chapters. School staff had limited knowledge of the legal framework for children with dyslexia-SpLD and limited functional knowledge of dyslexia-SpLD itself. The lack of knowledge of the legal framework including the Code of Practice (Department for Education, 2015) is a major contributor to the identified knowledge gap for both parents and schools.

At the empirical level is the child identity and voice. This is in part constructed from the observance of academic progress and attainment: self-competency/self-perception; the narratives held about dyslexia-SpLD; the degree of social belonging and integration, and the child’s perceptions of self through their use of language and actions. All of these can be observed and lead to a perception of the degree of voice and presence of child’s confidence, identity and capacity for inclusion and agency.

In between these levels is the actual level, where structure and agency interact. Some of that is visible or partially visible and some is not visible. It is worthy of comment that in the critical realism framework, just because something is visible does not necessarily position it as an observed reality. Things can be partially seen but still not at the top empirical level. An example would be an intervention group, where the session may be observed but the nature of learning, and the other types of learning drawn from that event are contributing to much higher order realities. For example, Gemma highlights the impact of an intervention group for George her son: **“Ah look, he’s going off and he’s having special...” and having the mick taken out of him because that’s a social thing that they don’t want to have”**. The teachers may see one reality, but the child and parents may see others (represented on the graphic as a dash-dot green line).

The contested space can include for instance parents through agency activating a structural feature to counterbalance the force of other co-occurring features. The actual level

is dynamic and shapes what is seen as observed realities. When Macdonald (2019) described how the context may shape whether an impairment became a disability, he was articulating the variable ways disabilities come into being. What this analysis does that is novel, is it articulates what some of those contextual factors such as the structural features of the Arc of Education, and through three further lenses which involve action and agency: one of visibility, one of discontinuity and disjuncture, and one of parental agency. It identifies why a focus at the actual level such as intervention groups may have been counterproductive, because they are focused on the within person, and not considering the without, that shapes the context. The focus on within creates limited inclusion despite the best intentions.

Intervention groups do not address how important relationships function, and are maintained in a dynamic environment, one in a state of flux. All these factors shape consequential inclusion and provide an explanatory framework to answer the question: how differences in information processing and variability in literacy development shape a range of self and social constructs.

The Real level-structural systems that shape outcomes

At the real level (blue boxes on the graphic), four core systems were identified, all deriving from social or psychological constructs, Legal, Policy, and Financial frameworks and the theory and discipline of Individual Differences. These were identified through a process of progressive abstraction and retroduction. The core systems shaped the outcomes both at a general level and also for each child and family. All the frameworks were located outside of the school and family but had a bearing on how people operated in those locations. Each of the structural components had been identified within the data, but the visibility of the components was variable.

One of the broad observations in critical realism is that agency is insufficient of itself to overcome structure. What is required is another structure to override the first. In the case of

legal structure, this does have capacity to override application of policy and finance. However, access to the legal framework was something of a cliff edge phenomenon: parents either did or did not know; there was very limited evidence of partial understanding, perhaps best captured by Oliver when he commented:

OLIVER: *We were at one school where they said well there's a lot more children worse than he is.*

I: *Oh yeah I've heard that before.*

OLIVER: *He's effectively not thick enough*

And Penny

PENNY: *He just, because he's not deemed severe enough, severe enough to be statemented or now, individual education or health care plan or whatever it's called now,*

Neither parent went beyond the school feedback of the child not meeting thresholds. Obliquely this is indicative of the relative social-professional authority that parents generally held about teachers. It was generally assumed by parents in the data that teachers would be working in their child's best interest, and assumed they knew and understood both dyslexia-SpLD and entitlement to support. This is where the role of the knowledge gap is influential. In both Penny and Oliver's cases the information provided elsewhere in the interview suggested they both would have qualified for statutory needs assessment. For instance, Penny was describing a child who was in Year 6 but could not spell or write at a Year 1 level, while Oliver's substantial contribution (£500 per month) was not sufficient to mitigate the downward trajectory of his son's attainment due to literacy difficulties. Karen was a case in point: when her son was thirteen, she suddenly found out that his reading age was eight, in spite of her active involvement and best endeavours and engagement: **"now, they have just done some reading and he is at a reading age of eight and he is thirteen. So, he is very far behind"**. The impact of the gap in knowledge and awareness was potentially very significant on outcomes for these children, and of potential importance to other families.

The legal framework was the most stable of the three socially constructed systems. Policy and Financial systems have consistencies and structures that have relative stability from one administration to the next. They are nevertheless open to political shaping and prioritisation or, in some cases, radical reshaping within each administration and as such represents a democratic form of influence. However, they too could evolve and be driven by local policy and its applications. This is an area of inquiry such as the work being undertaken at the Institute of Fiscal Studies (Johnson, 2020).

The final framework is one of individual differences. This again is an abstract construct which seeks to describe enduring characteristics that can enable individuals to be grouped by similarities; how an individual differs from the wider peer group. It has been developed as an academic discipline and has been heavily applied, as illustrated in the literature review, in the field of dyslexia-SpLD and inclusion research, with constructs being reified and then subject to measurement. Critics such as Richards (2010) have noted that the reification process can both create and illuminate features associated with cognitive and social constructs, and that what may appear enduring could be more heavily influenced by situational factors than may be always appreciated.

However, the use of cognitive measurement in research has allowed finely grained analysis of how different groups of children are similar or different. That in turn allowed the sorting of interventions into those with little merit: good ideas but less effective than hoped (for instance the application of Fast For Word programme that did not have the level of efficacy originally perceived (Halliday, 2012; Halliday, 2014)), and ones that work which have been discussed in the literature review, such as van Rijthoven et al. (2021). However, the common features that are found for children with dyslexia-SpLD are only a partial account against recognisable metrics. Other elements, for instance the interrupted attention and

discontinuity, are less open to common measurement but could be and were, in this data, observed.

The Actual level, the contested business of education

The Actual Level

The largest grouping of data findings was the combined section of Facilitation, Adaptation, Alternative Pathways and Effective Agency. This combined section was about positive activity by both parents, teachers, and other professionals as well as reports of children's activity. It included when another had provided an important bridge through information or help (facilitation). It included the ways and means parents and teachers used to develop alternative pathways to secure support or access to overcome barriers. This could include changing schools, different forms of activity and agency or drawing down from the real level such as legal. Effective agency was when there was activity which resulted in significant change and repositioning, often drawing from other sources such as reducing the knowledge gap at the actual level or Legal or Policy at the real level, along with experience. The latter point around how the knowledge gap was bridged was markedly apparent in the longitudinal group of parents, but also seen in some of the general parent interviews. The examples, also by implication, alluded to the types and forms of resistance they had overcome. The material has been explored through the three central results chapters.

So too has the intervention, accommodation, and remediation (parent led) feature. This fell into two forms: that which was provided out of school, and the agency by parents to facilitate school activity. The different forms of agency were linked to how parents enacted accommodation or remediation strategies as discussed in chapters 4 (Arc of Education) and 7 (Agency). However, as the case of Yves, Yasmin and Yvette illuminated, it was the distress in the child that was the significant activator of action; poor quality progress was not always of its self-sufficient to move a parent to direct action. Beth for instance, reflecting on Bob's Year 3

education commented: **"I maybe sat back on my laurels a bit because he was happy, he liked the teacher and he was making some progress"**.

Linked to the above was the degree of parent and child resilience, and the limitations of it. The challenges parents faced in seeking to enact inclusion for their child were considerable both in time and cost, and also in a very different life experience for their child and themselves. The level of support some parents needed to provide due to the lack of progress of their child would suggest that they may have been able to access some aspects of educational and social financial support (e.g. Disabled Living Allowance - DLA), had they had the needs properly recognised. So, the burden they carried was not even being mediated through the system designed to provide support. This was only true of some of the participants' children but represents an important gap of unmet need.

Individual differences and discontinuity and disjuncture

The way in which children differed from peers was possibly the most salient feature and the one most readily identified in the data by parents and teachers. It was the ubiquity of the differences that was used to partition children into groups. These were groups based upon age related expectations and not on potential or capacity, as illustrated by Rachel:

RACHEL: ***But he does say that sometimes when he was in a maths group, the lowest maths group and the children were just messing around, and they didn't want to learn, but he wanted to learn which was frustrating for him because he is quite good at maths, so in the end***

I: ***So why, if he's good at maths is he in the lowest group?***

RACHEL: ***Well now he's gone up one. Because with dyslexia you have to... it's like reading and things as well***

The individual differences construct was applied in practice through the partition of children into attainment groups. It has also dominated the research literature around dyslexia-SpLD. A substantial body of this inquiry has made use of measurement of individual

differences, while other research from the qualitative tradition has made use of observation. Both forms of individual differences were covered in the literature review.

As Rachel's extract illustrated, the construct can be bluntly applied: difficulties in reading constrained expression of maths ability, so a child becomes inappropriately located in the system at the lowest level. This is the rationale for the low position of Age Related Expectation (ARE) groups and intervention in the actual, and why the discontinuity is posited to influence them. Such disjuncture for a child then causes further challenges to identity. In this respect individual difference was a driver of both parents and schools, and it can also contribute through the nature of the differences to the disjuncture and disruption that children with dyslexia-SpLD experience.

Interaction of the Actual level features the impact of agency on structure.

Participants in the study, both parents and teachers, all identified how individual teacher agency was an important component for mediating the risk to the child being close to the edge of failure. In the accounts across the results chapters, the formation of a bridge between the home and school worlds was a repeating pattern in accounts of less stress and perceptions of effectiveness of education. In the graphic that is represented by the two lateral dotted lines, where information from the school linked to the school attainment and support (ARE group allocation), was used by parents and teachers to facilitate progress and access. The facilitation block was a combination of teacher and parent agency accounts.

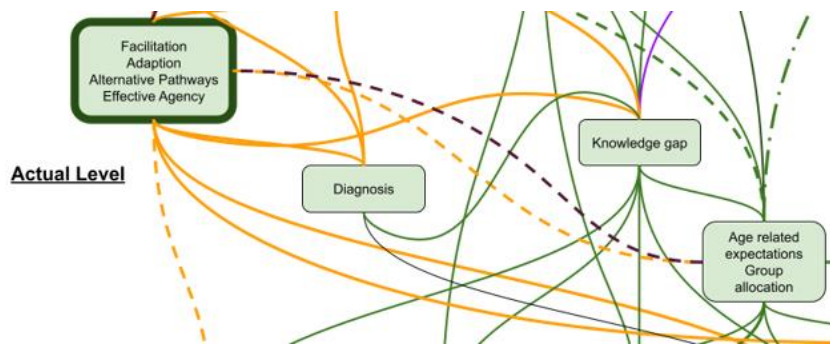


Figure 26 Extract of factors mediating collective parental perceptions, understanding and enactment of inclusion

The role of the teacher or school leader in circumstances where a child is operating close to the edge of failure is represented by the dotted gold line running from ARE groups to the Facilitation box. It involves working with parents or other school staff to put in place accommodations and remediation that reduce risk rapidly, and enable alternative access as required. It may also include longer term intervention such as use of technology or different strategies of learning. An example of effective agency by school staff was the agency by the teaching assistant for one of the pupils.

PARENT 5: *when he was trying to hide things or not work a sensible way or not use the laptop, they basically turned round to him and said do you want your GCSE grades and he's like yeah and they were like, you're going to have to use everything that's been given to you, you're a bright kid you should use it, you must use it and it's perfectly alright for you to use it.*

Alternatively, parents see the system for what it is and attempt pre-emptive action

OLIVER: *Really the thing we've been working with both of the boys is getting strategies in place so they can actually accommodate the structure they've got to sit within.*

The structural features were modified, constrained, or promoted by the agency enacted by parents, school staff/others and the child, and in turn created emergent properties, manifested at the empirical level. Some were positive, for instance the outcome from the

assertive outreach of the teaching assistant was of ownership of difference; others such as bullying described previously were negative.

Emergent properties and the observed realities of child identity

For this study the individual differences of processing information and inability to acquire literacy skills commensurate with peers led to group allocation. In some but not all cases, as illustrated by the case of Yvette and her children, Yves and Yasmin, discussed previously, that combination resulted in the repositioning of the self, and emergent property of anxiety and depressive features for Yves, but importantly not for Yasmin. The mother attributed the difference in development to the quality of each child's peer group, although other features may have played a role.

The role of the real level in constraining other structural features, application in practice

In examining the accounts provided by the parents there was little difference between the level of difficulty Thomas was reported to have and his attainment levels, and that of Nathan. However, the projected trajectory was very different. It came down to Nora's willingness to challenge (forthright agency) and the lucky break of attending a legal seminar on securing additional support for a child with dyslexia-SpLD (knowledge gap addressed). A SENCO at a school they had visited when considering a further move had suggested they look at specialist school (facilitation) in the region, Nora went on:

NORA: *Principal there said well we're having an open day, or open morning and we've got lawyers, solicitors coming down and they'll be talking about dyslexia, so why don't you come to that morning. So we went to that morning and that's when we found out a lot more. We spoke to one of the solicitors there and also the principal and they said we suggest you do this, this and this So we went back to school and then we had this meeting and [Principal EP] said this isn't a review, an annual review, this is more of an interim meeting, which we need to have. And from that meeting she advised the school to get the specialist teaching coordinator to come and assess Nathan, to find out where he was and what interventions and input the school would need to put in.*

This is perhaps the most graphic illustration of many of the accounts in the data: how small acts of information sharing or low-key assistance had profound impact, and different forms of agency interacted. In this case, the degree to which access to legal knowledge changed the way the rest of the system responded and how particular forms of parental agency worked, to secure a redefined inclusion for their son Nathan. The eventual outcome was specialist placement where he was able to develop and capitalise his strengths.

This was a drive for different provision, one with the promise of inclusion for celebrating strengths in the way Wendy described: **“I think inclusion is that everybody has to have something that they can shine at and be good at”** and for future social possibilities and securing GCSE’s. Across the accounts it was these idiosyncratic interactions that often had a role in shaping a child’s future: it was education and inclusion by happenchance.

For the parents that formed the longitudinal group the contested space was in the consistent application of the provision, with all the parents having to go back each year to insist on application as one of them noted: **“I’ve had the same issue [legal provision not applied] each year”**. However, what this does suggest was that parents, whether they had legal protection or not for their child, had to engage in the work of negotiating with the school to meet needs. Policy and finance played a substantial role in creating the contested areas and this is referenced in the graphic on the influences of resistance. Although not directly dealing with dyslexia-SpLD the same system resistance to acknowledging need and acting on the visibility of difference has been found by (Cullen & Lindsay, 2019; Lindsay et al., 2020) as for dyslexia-SpLD by (Leitão et al., 2017; Levi, 2017a)

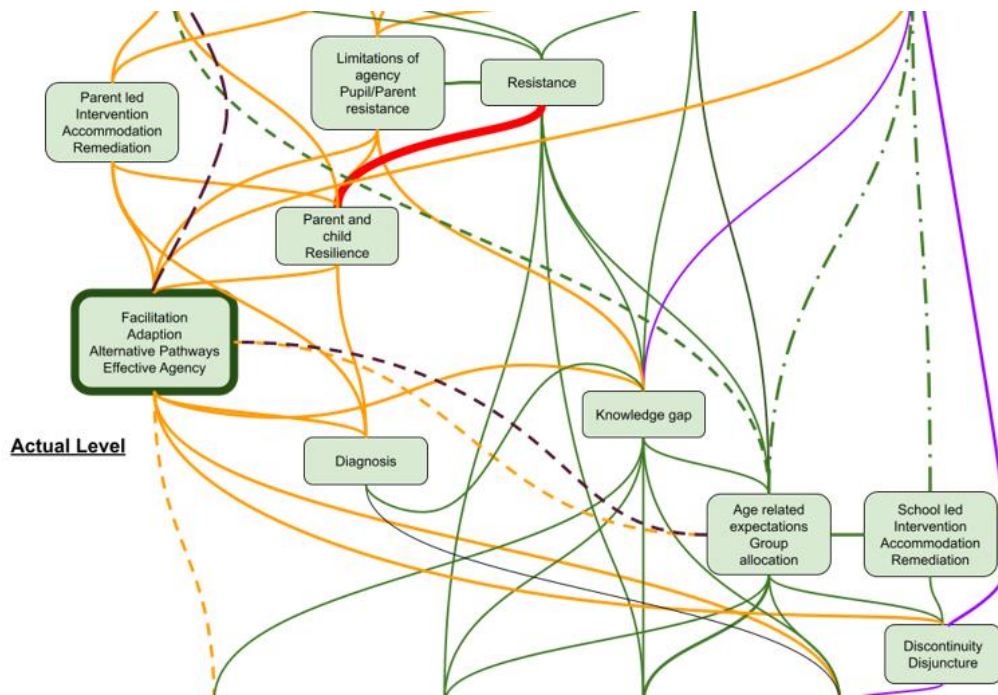


Figure 27 Extract of the actual level identified components derived from the data

The resistance that parents of children with EHCP's in mainstream education encountered was suggestive of the general level of resistance and complexity, presented in an abstract form above, by the red line.

Inclusion for children with dyslexia-SpLD is a process of ongoing developmental challenges and educational and social gaps that need to be bridged. That bridging from the data is not completed in a consistent way across the Arc of Education by the school in the way typically developing children experience. Parents then have to consider if and how to enact inclusion through either forthright challenge to a school, or by engaging in subversive or just compliant agency; the latter may not bring inclusion or educational access. The balance of judgement is to secure support without confrontation if possible. For some situations there was the option for parents to change schools and about half the parents did so to enact fresh starts. For others it was not the case, or it was very difficult: they had to make decisions around the implicit perception of risk of wider compromise of children's educational experience and seeking for the school to adapt. An example was when Beth had challenged Bob's first school around his lack of progress and then found the teachers took against her son:

BETH: He was lazy. I said: 'he's not lazy, he has a difficulty'. 'No, no I think you'll find Bob's just lazy'.

Some of those accounts are articulated in chapter 7 (Agency); the consequences of potential breakdown in relations, or high levels of stress was a constraint for parents. For example:

VERA: the night after we talked about it Vince [was distressed] because he was so nervous about the prospect of moving school

One of the novel contributions of this study to the field was the identification and recognition of how discontinuities and disjuncture which were expressions of individual differences as well as system-led disruptions, contributed directly into child self-concept, but also shaped the types of intervention, its success and the group allocation by a school. An example was Xara's father saying: **"she 'goes to the group of the dummies', as she says, 'she's dumb'"**.

The Empirical level

This is the level of observed realities, i.e. what can be seen, which when the focus is an intangible such as inclusion, is an oddity. Perversely some of the material at the actual level which looks to be observable realities such as intervention groups are not as empirical as may be thought. From this analysis what can be seen is not the doing of an intervention, rather it is the practical evidence of academic progress and attainment. What can be heard and understood are oral accounts and narrative of dyslexia-SpLD or of the child's self-perception, labelling and expectations as they navigated daily life. The children also observe the world and themselves. Other observations where the collateral evidence of isolation, bullying or withdrawal, or alternatively capacity to join in, and be part of the group. These were the surface qualities that arose as the product of interaction and events at the actual and real level.

Across the results chapters, accounts of each of the features in the graphic have been explored. Parents used outside resources to try and fill gaps in learning and skills, but these were not just limited to literacy difficulties. They addressed a wider range of needs and promoted areas of strength, including hobbies such as swimming or Brownies. These may have been ordinary type children's activities, but they were approached with strategic and protective planning. For instance, Tracy paid for individual swimming lessons to avoid comparison and maximise teaching, Susan's neighbour was the Brownie leader. They endeavoured to work with schools and, depending upon their level and type of agency, they had variable success. However, there were also marked limitations to their agency, which while on its own was constraining the structural impact, was insufficient to overcome the structural features, unless they invoked additional resources such as legal knowledge.

The broad red line representing the different forms of agency was the point of maximum conflict between system resistance and parental activity and action. A parent's capacity to be resilient could be limited by the ongoing nature of the contested space, or due to limitations of health or finance as found by Muter and Snowling (2009) and reinforced across many of the qualitative studies. In this study as one parent disclosed:

YVETTE: *[...] on financial grounds because we had to pay for it which is a lot, and also I find it, I don't tell people [...] this, but I have chronic fatigue and I just find it too much to then at the weekend be rushing around and having to do it.*

Inclusion for many for the parents was an illusion; it served to act as an additional barrier because the focus was on normative outcomes which favoured the majority. Across time the data shows how inclusion disadvantages many children and sets them with a limitation of wider social inclusion by the end of their education. In this study it was the activity of parents that sought to mitigate the ordinary story of dyslexia-SpLD outcomes, and through their effort open opportunity by trying to ensure they could place their children within

the 35% of pupils with dyslexia-SpLD who do meet the national averages by the end of their education; that their voice and identity had some mechanism for repair, and with a hopeful future. Not all the parents were going to be successful, and the school/educational structures and systems had seemingly failed these children. There were also accounts of how teachers, often seemingly working in their own subversive ways, sought to support children at risk and do what they could. There was only one example of the whole school package working effectively: the rural primary school. However, there was no indication the follow-on school supported such a way of working.

Summary

A number of novel features have been identified in this study, made possible through the development and application of a novel research methodology; namely the use of substantial case studies analysed from the critical realist perspective (Easton, 2010): one not used in education widely, or applied to this topic before. Critical realism has had limited presence in education research, the main contributor being Macdonald (Deacon et al., 2020; Macdonald, 2010; Macdonald, 2019; Macdonald et al., 2016).

This novel approach allowed for several elements to be identified, as illustrated in the graphics of elements not previously recognised (Figure 20, Figure 21 and Figure 25). Their influence on how these enhance or constrain other elements was identified: the discontinuity and disjuncture; and the types of agency by parents, were two important aspects.

From the data, multiple interpretations could be constructed from the accounts of parents and teaching staff, with often a description of a single or discreet event reflecting several interacting features. Indeed, it was the overlay of features and the many ways it could be configured that made the analysis of the data quite as complex and taxing as it was. The account presented here is one of a number that could be offered, but it provided the most straightforward and comprehensive account to answer the research question: How do parents

of children with dyslexia-SpLD perceive, understand and enact inclusion, and meet the challenge put down by Lindsay (2003) to explain through a rigorous approach the interplay of multiple factors that shape inclusion. This is an interpretation consistent with the participants', and the researcher's experience and insider knowledge. The graphic representation in Figure 25 identifies across three levels of influence, how groups of features emerge as a result of interactions of different structural systems with different forms of agency. These shape a child's ability to access universal education and their family's experience of inclusion. The important contribution of this study is the recognition that effective inclusion is not something done to a child in education, it is an outcome of the child's voice being heard and their unique presence recognised.

It is the emergence of their voice and identity that will enable participation and contribution to inclusion.

Chapter 9: Key Findings, Conclusion and Reflection

The study

Why was the study needed?

This study was necessary because despite the effort and commitment of academics, teaching, school staff, governments, and advocates over the last 40 years the outcomes for children with dyslexia-SpLD have remained stubbornly compromised. However, as the literature review identified there was an important set of assumptions being made and an important gap not acknowledged. Firstly, it was being assumed that education was something that took place in school, and the solutions to the difficulties of dyslexia-SpLD would be located there. The relevant authorities were therefore the school staff, and the object was the child. The voice of the child or the parent was not of significance or of salience. Starting with Riddick's work (1996) this did start to be challenged but remains a relatively poorly represented area and the dominant accounts are still school focused and child as object. Which led to the second point, the identification of the knowledge gaps both for the practice and field of education and for parents. Those included gaps around dyslexia-SpLD, inclusion and how parents exercise agency to support their child, the constraints on the support they can provide, and the implications of this.

Unlike many other factors that limit children's life opportunities, the teaching of literacy and access to education is within the power of the education system to address or at least to mitigate its impact. In the 2020 English school census figures (Figure 5) 145,000 children across all in mainstream education had been identified with Specific Learning Difficulties, and only 35% of those in Year 11 secured Maths and English for GCSE, a pattern has persisted over recent years. By implication, the findings from this study suggest pathways that could in future limit the consequential social impact for a substantial proportion of those

children who experience the current UK education system. It also raises some pertinent questions about the values placed on children and how they and their families are valued.

The research question **‘in what ways do parents of children with dyslexia-SpLD perceive, understand and enact inclusion?’** asked what participants saw, understood, what they did as a result, and why. It sought to identify, through innovative research strategies, the gaps in understanding, function, and practice. As an education and psychology-based study it used a novel research approach and examined what happened or what did not happen. Using this strategy, I explored how parents understood the education system’s notion of inclusion for their child with dyslexia-SpLD, and why in many cases it was problematic. The study examined how parents sought to support a version of inclusion for their child, and how that enterprise shaped the formation, experiences, and cost of inclusion for both themselves and their child. The findings from this study suggest how identified gaps in knowledge, sources of knowledge including parents, understanding of risk and conceptual formulations of dyslexia-SpLD and inclusion had the potential to be challenged and facilitate meaningful change beyond the confines of the study.

Approach

The study’s methodological approach to the material gathered in interviews was to examine the descriptions of what parents reported they did, the ‘enacted’ part of the research question, and through that seek to explore their accounts for what had driven their actions, by what they had seen and how that had been understood, the ‘perception’ and ‘understanding’ part of the research question. Such an approach allowed for depth of understanding and the identification of a pattern; the demi-regularities across a range of individual circumstances.

Several novel findings were made across the study; those identified had a role in shaping how access to universal education through the application of inclusion was experienced by pupils through their parents’ eyes. Four main findings were the: discontinuity

and disjuncture continuum with its three levels (micro, meso, and macro), how children operated close to the edge of failure, and the three forms of agency parents used (compliant, subversive, and forthright), as they sought to manage inclusion. These findings emerged from an examination of two forms of visibility, behavioural and epistemic, and created the circumstances of enabling or disabling inclusion.

Discontinuity & Disjuncture

The accounts offered by parents suggested that the individual differences of cognitive processing for their child precluded the fluid typical development they observed of other children and linked to that educational development. Parents and teachers both gave accounts of children with dyslexia-SpLD having greater but uneven challenges and disruptions in both daily life but also in their capacity to meet the performance needs of the education system. Parents went to effort and expense to mitigate the impacts in daily life and did what they could with respect to reducing immediate and long-term impact of the child and their future options.

This contrasted with the broadly observed way typically developing children could manage. Those disruptions and the consequences were cumulative. Starting at a very early stage in education there became a poor fit between the child, the setting they had to function in, and the social context. This from the data had progressive impact.

Micro

The micro level of disruption was most easily identified when the child was in secondary education but had occurred throughout the span of education. There was a gap created between expected independence and agency by secondary education and the individual capacity. This was due to the within child differences of information processing, so the profile of difficulties became expressed. The discontinuities at Micro level generated small but persistent disruptions in function, causing the child repeatedly to stumble in their work,

social role, and generate negative perceptions of them by others. The common prevalence of the disruptions contributed to a persistent sense of disappointment and were part of the account where the child regarded themselves as 'stupid' or a 'failure'. The parental accounts suggest micro discontinuities were accommodated by parents and some teachers to the extent they were overlooked, and in later education there was evidence of how as parents they sought to support and manage those features to reduce negative social impact.

Meso

While the meso level of discontinuity had visibility when the child was unable to efficiently learn and become age-appropriate skilled in reading, writing, and spelling, the disruption was not circumscribed. The discrepancy had social, emotional and psychological effects, in part because those skills permeated the education context and because of their wider impact. Those ramifications (for example bullying) became emergent properties with their own profile and trajectory as well.

The meso level is what parents thought of as 'dyslexia', it was the account of poor fit and unexpected difficulties. It also was an account of poor-quality inclusion or inclusion as a form of disablement. Their interpretations of what they saw and understood reflect an array of sociological frameworks used to describe dyslexia-SpLD. Of interest, parents were not using a singular description but called upon a range of accounts/frameworks and descriptions representing lived experience in and around education; and how being an outsider inside education mattered to the child and parents.

By implication the discontinuities also generated disruption to the institutional and social form of inclusion. Macdonald (2019) has previously given a summary account of six sociological frameworks used to position dyslexia-SpLD from a sociological/research perspective. Four of those used by the parents include the bio-psycho-social framework, the social model of disability, the affirmation/post-structuralist framework, and the neurodiversity

framework. The novel finding in this study was how parents used the different forms identified above, sometimes singularly but also concurrently, to position their child and self and to navigate pathways through for themselves. However, to all parents, 'dyslexia' was an object - it was real, it provided a vehicle for an explanatory framework, and had manifest consequences. The term was only problematic with respect to the dealing with resistant parts of the education system that challenged the term, but did not address the reality or the persistent, though intermittent, experiences of epistemic injustice.

Macro

The macro level marked a shift from discontinuity, which by implication had possibility for repair, to disjuncture where there was a disconnect and the need for explicit action to change trajectories. The boundary between the outer edge of meso and macro could be blurred or clear. In the data that rupture occurred due to the cumulative meso level failures or because of structural features in the Arc of Education. The failures to provide mandated support, for instance the case of Dave and the missing teaching assistants were at the mild blurred end linked to the meso level, but the impact was immediate and negative; forthright action by Diane and restoration of the teaching assistant resolved the matter.

However, it was also an example and indication of how close to the edge of failure children with dyslexia-SpLD operate in an educational context. Small changes could have disproportionate impact, and this was a recurring demi-regularity across the parental data. For a surprising number of parents, just under half of the interviewees elected to move school out of a standard phase of education. This was a quiet form of macro level failure. For others, the breakdown was traumatic, exemplified by Lucy's account of Larry (page 211) and his throwing the chair across the classroom. The account of Larry stemmed from a major form of epistemic injustice where the mother Lucy had taken time and effort to seek to manage the transition to the new school, provide information and negotiated a support package. Literally nothing was applied, communicated or recorded on records. Larry eventually erupted with violence. This

was a case of a child operating very close to breaking point and something tipping it over. In chapter 6 (Discontinuity-Disjuncture) the case of Kevin was considered as again his mother Karen provided a clear account of how a child can operate close to the edge of failure, be under stress and small changes having great impact. However, looking across the data less dramatic forms were evident all the way through the accounts. These are children who, from the parents' accounts, are persistently under pressure. The impact of that pressure on the self and quality of learning is worthy of further investigation.

Contribution to field

The contribution to the field was to position what has been the contested space about dyslexia-SpLD, its diagnosis and the skill of reading and spelling, and to demonstrate as phenomena how it formed part of a continuum of functionality, with an impairment – disability axis and sensitive to context. It also identified how cumulative risk and damage was sustained across time and settings. Further, that the shape of the educational structure, (which had been poorly articulated in the literature until this study), notably the 'segmentation' of experience within the Arc of Education, exacerbated those risks. Those were demonstrated by Tracy and her son Thomas, (see page 200) who at age 11 had a reading age of 6, despite 7 years in primary education. He was passed from teacher to teacher and no appropriate action had been taken.

There were a significant number of accounts of parents describing their child being bullied, or their child adopting strategies to mitigate their risk from bullying and humiliation. Principally through hiding evidence of their difficulties from peers and teachers or socially withdrawing. In some cases, the psychological consequences were well into the realm of mental health difficulties. These were significant markers, but their link to both the structural aspects of the education system and the way the children were positioned within a continuum of disruption has not been articulated to date.

Agency

The other important novel contribution was the identification of the different forms of agency parents enacted as they sought to manage their perceptions of risk towards their child, and the deficit in inclusive educational experiences they identified. Parental agency was an important but unrecognised feature of school inclusion. The different forms of agency had different impacts on the type of support the child was able to access and the facilitation of inclusion. The identification of subversive agency was a notable novel finding, and one that has been overlooked in the literature.

Compliant agency

Three forms of agency were deployed by parents. Compliant agency was the first of these, in which the parent went along with what the school (or services) asked, as long as the school processes did meet need, there was some progress, and the rural primary school was an example of that. The processes that the specific school had deployed included detailed support, critical analysis, dynamic assessment and intervention, recognition of the limitations of interventions, partnership, and a willingness to call effectively for Local Authority action marked it out from all the other accounts. As a school they were an outlier. Compliant agency had a tendency in the accounts to drag out the timeframe for accessing effective support (if it was possible to secure) and leave a greater pattern of damage. Delays to assessments were the common account but also delay in providing the right level of intervention. Lucy and Larry were a case in point where diagnostic processes took over 18 months but with no clarity or action at the end.

Subversive Agency

The more usual strategy was for the parent to engage in subversive agency, this is a novel finding. This form of agency occurred the parent perception was the school was showing resistance or inertia around the need to change, or to do something different, in order to ensure the child was not left behind their peers. There was a difference in the perception of

urgency and necessity to act. Such a parental strategy was designed not to directly challenge, but to manage the perceived inclusion deficit from outside. For parents it involved substantial and sustained commitment of their resources be it, effort, emotional costs, time, or money. Consistently there was use of additional focused teaching, either in the home or through paid support. There was investigation around finding out what the problem was so it could suggest ways of addressing difficulties, (often in the form of assessment for diagnosis), there was the sourcing of knowledge through community networks and public sources so they could chart a path. The main focus was literacy, but it was not the only focus. There was also wider social activity for holistic improvement including physical and social domains. Importantly there was also the support and development of areas of strength, attempts at confidence boosting and the way parents provided alternative identity or dyslexia-SpLD narratives for a child. This counter narrative was used as a defence against those provided to them by their peers or some school staff. For parents who had dyslexia-SpLD themselves there was the modelling of resilience and resistance.

The subversive form of agency generally mitigated the impact of discontinuities at the meso level. It did not however necessarily secure inclusion with peers, there was accommodation, rather than remediation with its needed linked progression to independence. In some cases, the massaging of meso level discontinuities meant function in one setting was sustained to a level, but the child was poorly equipped outside of that specific setting and could significantly fail if it changed. An example was Kevin's transfer to senior school, where he found he could not perform the basic literacy-based functions of copying off the board and recording his homework. Subversive agency is therefore also complicit in the sense that it conceals, rather than reveals, the extent to which inclusion is failing, or failing to occur.

Subversion despite its limitations was however in several cases the only realistic option open to the parents. The sourcing of outside help, sometimes contemptuously referenced in

some quarters as the 'dyslexia industry', was down to the longstanding and documented failures of schools and Local Authorities meeting the reasonable expectations of parents and their children. Those were that their child should have access to universal education, one which also included the acquisition of appropriate skills of numeracy and literacy, and potential for future options of independence and health through securing the fruits of education.

Forthright agency

The securing of sustained and comprehensive support generally only happened with forthright agency, which was clear and unambiguous in the need for action. The legal framework could provide a means to overcome the most trenchant resistance. However forthright agency could be low key, as in the rural primary school when Gemma, the mother of George, recounted in the visibility chapter going from teacher to teacher at the start of each academic year to ensure George's needs were understood. Alternatively ranging to the direct confrontation of Nora with the Local Authority case officer when she and her husband took the Local Authority to tribunal to challenge provision. The aim in all the actions could be inferred from their accounts for the children to secure routes to long term agency and independence, a sense of autonomy and success, but also to avoid situations where distress was likely to be generated. Sometimes that action occurred within just a phase of education, the physical space and culture a parent could see at that point in time. In others it was longer term trajectory a general appreciation of a need for progress at one point determining capacity at a future point. Perhaps the final word on this is best summed by Eric on his reflections at the end of his interview.

ERIC: Well just to recap what went through my mind was the influence of one of my great heroes Winston Churchill who in the darkest days of 1940 when this country was at its greatest need he um was always saying to people that you never, never, never surrender and one can draw comfort from that and can parallel it with the assessments that

we do and indeed um President Roosevelt at the time said of Churchill he mobilised the English language and sent it into battle.

*I: (laughs) that's fabulous and that's what you've done too (laughs)
Thank you very much indeed.*

Impact of agency

Inclusion, partial or lack of it, was a marker that suggested to both the child and parent there was not equitable access to education. One of the points of conflict with schools was the expectations and knowledge by parents of their child, and their potential. This in several cases contrasted with those of the teacher and school leader. This was reflected in the teacher accounts, with some schools downplaying expectations to those that could be met within their resources. Given the lack of spare capacity individual teachers had, their overloaded schedule and the limitations on their areas of influence as described by the experienced teacher Hara (see page 180) that was understandable. However, it is a challenge to the culture of the system. And it also possible with this to understand why some teacher's actions could be understood as subversive as well. That systemic feature generated conflict with what the child had potential to achieve and what the parents had hoped was possible.

The longer the meso level discontinuities persisted the greater the loss of potential or good outcomes being realised was likely. For those cases where change occurred, such as moving school the improvement could be marked as when Yvette moved Yves, his health and general mental state were transformed. So too for Emma, Nathen, Bob, Dave, Clare, Andrew, Larry; all of whom moved out-of-phase of education. The salient question was why was a change of schools necessary? For the most part though parents their actions or non-action earlier in the Arc of Education were only recognised for their value or limitations towards the end of the formal education process (see page 265). The difficulty in having clear sight of the future needs across the Arc of Education in order to secure inclusion as an ongoing state,

remained one of the important findings of this study with respect to potential to change current outcomes.

Finally, with respect to agency, another important novel contribution was the finding of how distress played an outside role in priming and initiating parental agency in ways that have not been identified or described previously. It was clear from the data that it was not that parents perceived risk from poor literacy and acted. Instead, it was the damage to a child's sense of self through disruption of inclusion and the contingent distress that moved a parent to action. Failures of inclusion in education were integral to accounts of dyslexia-SpLD. This was identified by parents as the driver for their child's difficulties, rather than the feature that made it visible, which was a failure of inclusion. This is an innovative way of understanding what drives parents' action around dyslexia-SpLD, or not, and has potential as important contribution in understanding how a profile of failing education can be overlooked.

Summary in relation to the research question

Parental perceptions

The overarching account of parental perceptions from the data and presented in the results was that for parents "inclusion", as currently configured and described by inference and practiced in education, did not work for children with dyslexia-SpLD. It was an illusion. However, there was unevenness in most of the accounts which suggested that intermittently individual actions had made a time-limited difference. Certain features were linked to positive experiences such as trustworthiness, the taking of an open and critical stance on observations (avoidance of assumptions) and making use of parental accounts, with presumption in favour of the validity of the parents' account. This, along with quality knowledge around dyslexia-SpLD and access to an expert made a qualitative difference. Parents had expected inclusion when their child started school and maintained that expectation for the most part. However,

they found that in general teacher knowledge around dyslexia-SpLD was lacking, and their child (and they) were a poor fit within the system at all levels.

The perception of parents was that they were on their own, and each parent had to learn for themselves. There was a point in the research where Oliver, having heard his fellow group member give accounts of their experiences, expresses relief **“For the first time for a very long time, it’s very pleasing to hear, it’s not a pleasing situation but it’s pleasing to hear other people with similar issues”**. That sense of isolation was pervasive across all the parental accounts and there was a sense that not only did their child not have access to peer inclusion, the same occurred for the parents too, and the burden they carried.

Parental understanding

Their child was not ‘making it’ and this was not expected. Further, typically parental expectations of school staff as being expert was misplaced and knowledge of and around dyslexia-SpLD was poor. Parents in this study mostly came to realise at varying points that if their child was going to have any chance of joining the adult world with options, they would need to act. They came to that point when they recognised that the schools they were connected too were unlikely to be able to meet need, unless additional actions were taken. That in the most severe cases of failure to make progress and access education included securing an EHCP or appealing provision had been taken. Finally, they realised that dyslexia-SpLD as a construct and lived experience was not viewed by the system as a significant form of disability, sometimes not acknowledged as a disability, despite the ramifications at the individual level. To deal with that they enacted different forms of agency and using their resources dynamically.

Researcher observation

As a researcher, what I was struck by was how many aspects of dyslexia-SpLD, education and rights the participants and particularly parents did not understand or had

misinterpreted. This gap was a greater obstruction than the education system was, which inherently had some safeguards in it. There were few parents who had grasped the power they potentially had, the knowledge that was available and the reasonable right to expect equitable education. Outside of those families who as a group did secure statutory provision, parents did not understand that it was the Local Authority that carried the responsibility for all children with special educational needs and provision and support was not entirely on the school. Conversely the capacity to engage in that challenge was not for everyone without some form of technical support, be it voluntary, or commissioned/paid for. The other pertinent observation was the role of happenstance in the fortunes of child accessing education; a teacher recommendation here, a useful seminar there, a chance meeting in a school playground. Happenstance occurs across all lives, but its role should be on the discretionary end of system not at the fundamental core feature end, certainly not as key feature for a child securing access to basic universal education. It seemed to me to be an inappropriate mediating feature.

Reflection

The nature of supervision

Adopting a critical realist stance for research was a risk. It was not established as a way of reporting in the field of education and its novelty was contingent upon ensuring that there were mechanisms to provide support and to challenge evidence and interpretation. The quality of reflexivity, the capacity to self-challenge and seek to engage in revision and re-ordering has been long recognised as fundamental in qualitative research. However, this work, which was anchored in critical realism, required a different degree of reflexivity. In part this was because the work was positioned from an insider perspective. I as a researcher had my own history, knowledge and experience that allowed recognition and access to findings and nuances that had been or could be overlooked by those with outsider position. Equally, like all the participants and notably the parents in the study, there would have been for me

unacknowledged misinterpretations and overlooked evidence. Critical realism required that those hidden or low visibility areas were examined. The team of supervisors served not only as technical advisors about the research process, but from their different research ontological stances contributed very different perspectives that could challenge my interpretation of evidence. Their challenge to claims, insights, and formulation of knowledge allowed me to understand my own position. The sessions were recorded and that moved supervision from a transitory point in time event, to an object that could be critically evaluated and re-examined multiple times.

The process of engagement

The time and commitment my supervisors invested in the project to support my work was considerable and allowed for the depth of investigation. Their principal role was to be a critical friend, to challenge and dispute the claims I advanced, to draw from their own knowledge about the merits of interpretations. It was in the reviewing of the recordings of the supervision sessions that the space between the original idea or writing and the critical stance was developed. This was the process of abstraction of data within research rather than abstraction of, or to, data. It was iterative in a way that Braun and Clarke's paper did not capture, there was not a smooth transition from one phase to the next, as their paper presented, but there was a recapitulation in this version.

The work was challenging, some of the accounts provided I found deeply moving, and provide an insight into the hidden world of distress and difficulty both parents and teachers seek to manage. At points it was appropriate when personal circumstances necessitated to rest the work and return. The use of NVivo helped in this respect as it was an effective database and allowed material to be put on pause and re-engaged with minimal effort. This on reflection is a strategy that requires a trustworthy team to support the investigation and is unlikely to be suitable for novice solitary investigators with limited real-world experience of a

field. It was however very useful as an approach and strategy to examine intractable or complex problems, ones that have not been resolved through standard forms of investigation.

The formation of the Arc

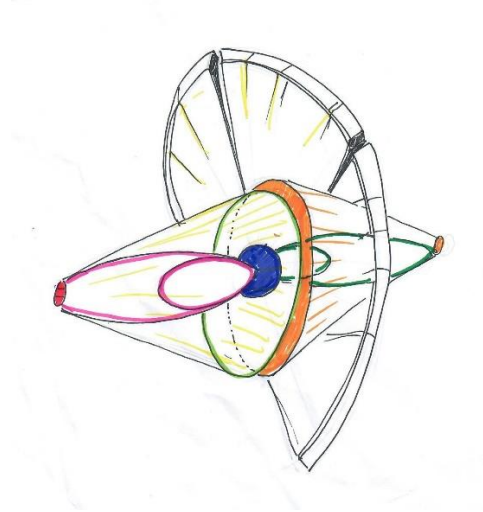


Figure 28 Original drawing of the Arc of Education: Angela Thompson June 2020

The complexity of the interacting features made the process of analysis taxing. The full complexity was acknowledged when in attempting to pictorially represent, I realised that a 2D version was not going to work, nor would a 3D version be using standard shapes. It took an original configuration in 3D to express the interrelationships (Figure 28), and this became the Arc of Education (Figure 20 and Figure 21). Such a shape also indicated that the education process was not linear or straightforward. It was not surprising that parents had found navigating the system hard and for several how they had become trapped in it. Nor was it a surprise that teachers may have difficulty seeing beyond the area they have influence over, their class. Both aspects contribute to disablement of the child, though neither teacher nor parent knowingly drive that difficulty.

Future directions

The Arc of Education provides a useful structure to explore current provision around the impact of aspects of education such as segmentation, the use of features such as Assess, Plan, Do, Review from the legal framework. It illustrates how the permeability between the

home school geographies impacts, how the child perceives this world, and in particular how those differences manifest following the 2020 pandemic, with the necessary dislocation of education. The role of mental and physiological health, its links to inclusion as central to dyslexia-SpLD are aspects that need rapid attention. Exploring the three types of agency parents use to support a child with dyslexia-SpLD in their quest for inclusion could be developed.

This is a study that has principally recruited participants from an English cultural heritage. That was not intentional, but it was part of a product of ethical issues and ethical constraints. I had purposefully not recruited in London as the profile of the Capital's education composition and outcomes is at variance with the wider English setting. It would be relevant and important to establish how many of the findings were culturally limited and to explore how different communities may manage engagement and agency and how that contributes to the type and nature of support secured.

The study opened with a personal account from my son about the failures of the education service to meet need, and shadows and reflections of that account were found across the data. For that story to change a radical restructuring of understanding about dyslexia-SpLD - inclusion and universal education needs to occur, and this study is positioned to start that process.

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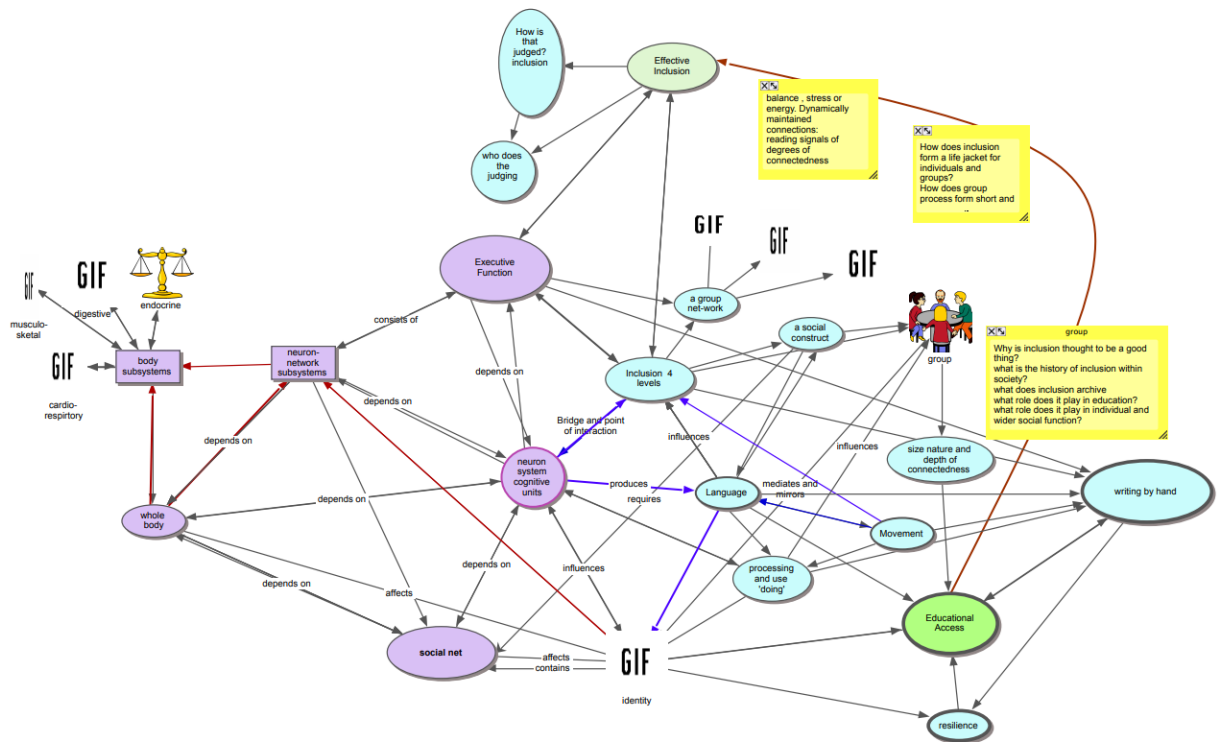
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Appendix A: Process of research

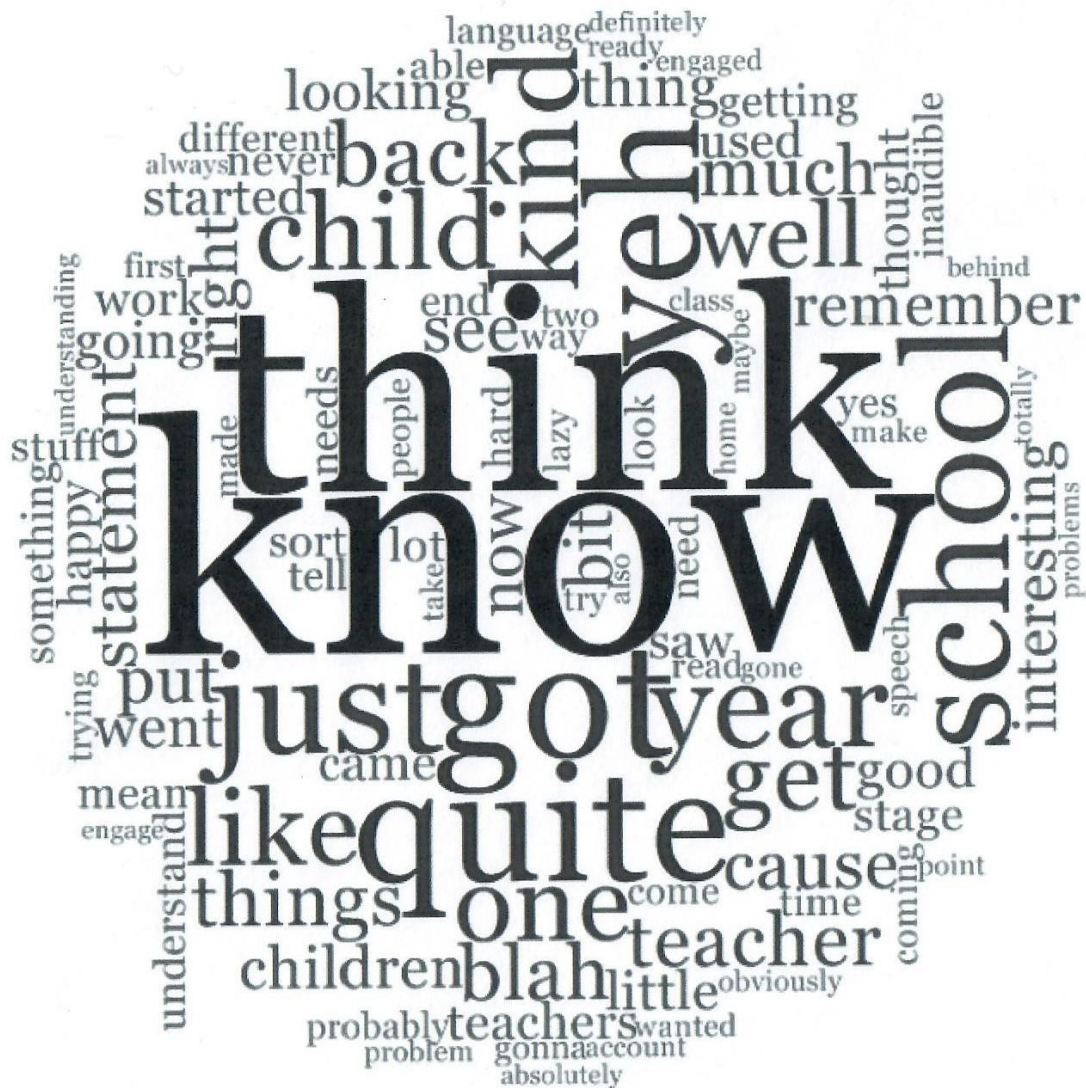
Sample exploratory mind map



This is an example of a mind map sketched over the summer 2017 using Inspiration software.

It explored the relationship between the internal world and the external world and inclusion.

Word Cloud



This is an example of an early word cloud run through NVivo on one of the interviews. It surprised me how dominant the word thinks and know were as they had almost blended into the interview of first listening. Subsequent listening picked up how much effort was being made by interviewees to provide parental support.

Academic community contribution

Publications

Carroll, J., Bradley, L., Crawford, H., Hannant, P., & Thompson, A. (2017). *SEN support: A rapid evidence assessment. Research report*. GOV.UK. Retrieved April 22nd 2021 from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/628630/DfE_SEN_Support_REA_Report.pdf

Conference papers

Inclusion, Parents, and Schools

- British Dyslexia Association Annual General meeting and members meeting, Coventry, January 2019
- Authors: Angela Thompson, Professor Clare Wood, Professor Julia Carroll, Dr Simon Goodman and Dr Sarah Critten

Mind the Gap: Inclusion, Dyslexia - SpLD and the Problem of Poor Educational Outcomes

- April 2018 British Dyslexia Association International Conference, Telford, 2018
- Authors: Angela Thompson, Professor Clare Wood, Professor Julia Carroll, Dr Simon Goodman and Dr Sarah Critten

The Role of Competence Beliefs in Teaching and Learning

- BPS Psychology in Education Specialist Section, Annual Conference, 2015, Liverpool
- Authors: Angela Thompson, Professor Clare Wood, Dr Simon Goodman and Dr Sarah Critten

How do you solve a problem called inclusion?

- BPS Regional Conference, West Midlands Branch annual conference September 2015
- Author: Angela Thompson

Poster

Dimensions of Inclusion: Some Critical Issues and Implications for Dyslexia Provision

- BDA international conference, Oxford 2016
- Authors: Angela Thompson, Professor Clare Wood, Dr Simon Goodman and Dr Sarah Critten

Appendix B: Ethical Approvals

Phase 1

Note: To comply with anonymity and confidentiality requirements, the details of the 2013 project are withheld from public view but are available on request

Phase 2

Project details

Applicant Details

| | |
|-----------------|----------------------------|
| Full name | Angela Thompson |
| Faculty/URC | University Research Centre |
| School/Dept/FRC | GLEA |
| Research Centre | None |
| Supervisor | Sarah Critten |

Project Summary

| | |
|---------------|--|
| Project ID | P61676 |
| Project title | Exploring inclusion in the context of meeting the needs of children with dyslexia in mainstream schools at key stage 1, 2, and 3: Qualitative perspectives of parents and school staff |
| Module code | PHD-CABS |

| | |
|---------------|--|
| Project ID | P61676 |
| Project title | Exploring inclusion in the context of meeting the needs of children with dyslexia in mainstream schools at key stage 1, 2, and 3: Qualitative perspectives of parents and school staff |
| Module code | PHD-CABS |

Brief Project Summary

Three groups will be approached to offer their views on inclusion processes for children with dyslexia from mainstream schools. The views of parents who have capacity to look back over all educational stages of statutory education, parents who are in those named stages, and school staff. The combination of perspectives allows for developing a coherent account of inclusion and dyslexia from different perspectives using a critical realism framework of research. Two sub-questions of research interest are: How have changes in the legal framework in 2014 and 2015 around Special Educational Needs (SEN) been understood and felt? And, how does inclusive education for those with dyslexia/literacy difficulties happens in real life?. The aim is to provide a coherent description of current management and practice, and then formulating a model describing effective inclusive education for children and families with dyslexia. This work will build upon phase 1 of the PhD data collection 2013/14. Due to changes in the law around Special Educational Needs and the refinement of the research question in response to the earlier data, it is necessary to capture updated and refined evidence.

| | |
|--|---------------------------|
| Start and end dates | 02 Nov 2017 - 30 Sep 2019 |
| Names of Co-Investigators & their organisational affiliation (place of study/employer) | - |

| | |
|------------------------------------|---|
| Is this project externally funded? | Yes |
| Who is funding the project? | has been covered with studentship from Coventry University from what was PBA and is now CABS /HLS |
| Has the funding been confirmed? | Yes |

Project Detail

What are the aims and objectives of the project?

This study's aim is to extend and develop phase 1 of PhD by exploring the realities of the educational arena as it relates to those with dyslexia or Specific Learning Disabilities (SpLD). In particular to ask those underrepresented in the literature, especially parents, about the insights and experiences they had about how the system works, or not. This is in light of the change of Education Law in 2014 and 2015 Special Educational Needs and Disability Code of Practice 0-25, which purportedly gave greater prominence to parental contribution, inclusion and mandated high expectations in terms of educational and life outcomes. To understand this perspective, it is also important to gather the views of person/s/teachers tasked with delivering education. Such information would be used in the development of a meaningful model of educational access and inclusion for children, families and schools, that can then be subject to future inquiry.

Explain your research design

The research strategy is qualitative and iterative, with successive points of data gathering, exploration and returning to and refining the research question. It uses interviews applying open questions within a semi-structured format to gather data around inclusion, both educational and social aspects, access to education, and dyslexia. Group 1 interviews would be a 12 longitudinal follow-up with the original parent participants from phase 1 of the study. [This group of parents](#) who would provide a mechanism for recruiting participants. Group 2, parents would be recruited through two regional [hyperlocal](#) snowball sampling via knowledgeable experts in the field. Overall it is a design that is inductive, and located within a Critical Realism theoretical and methodology framework. Interviews will be transcribed and subject to thematic analysis, using NVivo software and hand coding, to draw out the themes and substructures underpinning the narratives.

Outline the principal methods you will use

Individual and group interviews using open ended questions in a semi structured format will be conducted, recorded and transcribed. The interview questions have been developed from the analysis of phase 1 data. The thematic coding strategy using Braun and Clark's (2006) principles as developed in an earlier study will be applied. This will be used within the context of Fletcher's (2016) work describing a methodology for Critical Realism studies. Of interest in the analysis will be evidence that conflicts with earlier findings. Participants will be recruited as described above.

Animals and their habitats, tissues, body fluids, primary cell cultures derived from animal tissues (excluding humans) ☒

Hazardous substances ☐

Machinery & equipment ☐

Ionising Radiation ☐

UAS flights (drones) ☐

Environmental samples ☐

2 Are there any other ethical issues or risks of harm raised by the study that have not been covered by previous questions?

While these interviews are not out of the ordinary for research purposes, and not with high risk groups or covering high risk material, protection of participants

[This group of parents](#) is important and addressed. Specifically, for the follow up parental interviews from phase 1 of PhD they will be offered the opportunity to have their latest information confidential as well as anonymised. This is consistent with original ethical approval and arrangements;

[The original consent](#) did include agreement that for this group of parents they could be approached for follow up interviews, and that new consent would be sought if they agreed to participate. Standard arrangements for consent, anonymity and data security/confidentiality apply to the rest of the interviewees. A resource signposting of additional support contacts will be provided for each participant in case the interview throws up questions they may wish to follow up on.

Ethical review feedback

Exploring inclusion in the context of meeting the needs of children with dyslexia in mainstream schools at key stage 1, 2, and 3: Qualitative perspectives of parents and school staff P61676

REGISTRY RESEARCH UNIT ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

Name of applicant: Angela Thompson

Faculty/School/Department: [Faculty of Health and Life Sciences] FR Centre Advanced Behavioural Science (CABS)

Research project title: Exploring inclusion in the context of meeting the needs of children with dyslexia in mainstream schools at key stage 1, 2, and 3: Qualitative perspectives of parents and school staff

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

This is a well thought through ethics application that poses no serious risk of harm. As well as anonymity, full confidentiality for some participants will be given.

A full stop is missing from the end of the third paragraph of the gatekeeper letters. The letters are fine, although quite long. It could be worth including a telephone number as well as your email address.

2. Evaluation of the participant information sheet and consent form:

Typo on the PiL under benefits of taking part (though should be through). Otherwise the PiL and consent forms are fine.

Very thorough debrief.

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

☒

Approved - no conditions attached

☐

Approved with minor conditions (no need to re-submit)

☐

Conditional upon the following – please use additional sheets if necessary (please re-submit application)

☐

Rejected for the following reason(s) – please use other side if necessary

☐

Not required

Name of reviewer: Anonymous

Date: 30/11/2017

Appendix C: House of Lords debate on Warwickshire County Council

Hansard Volume 793

<https://hansard.parliament.uk/lords/2018-10-30/debates/EFC738AB-4006-4AA8-88EB-3488293D7F27/HealthSpectrumConditions>

Health: Spectrum Conditions

Question

Tuesday 30th October 2018 14:52:00

Asked by **Lord Addington**

To ask Her Majesty's Government what assessment they have made of the importance of identification of spectrum conditions, such as dyslexia, ADHD and dyspraxia, on (1) educational, and (2) other life outcomes.

Lord Addington (LD)

My Lords, I beg leave to ask the Question standing in my name on the Order Paper, and remind the House of my declared interest as president of the British Dyslexia Association.

The Parliamentary Under-Secretary of State, Department for Education (Lord Agnew of Oulton) (Con)

My Lords, our data collections do not separate outcomes of dyslexia, ADHD and dyspraxia, so we are unable to make such an assessment. In terms of destinations, after completing key stage 4, for those with SEN, overall in 2016-17, 90% of pupils with a statement or education, health and care plan were in sustained education, employment or training compared to 88% of pupils with SEN without statements, and 95% of those without SEN.

Lord Addington

I thank the Minister for that reply. I have made him and his office aware of the document brought forward in February this year by Warwickshire Educational Psychology Service, called Teaching Children & Young People with Literacy Difficulties Practice Guidance, which is very similar to a document that appears on the Staffordshire site. This states that dyslexia effectively is not something to worry about. It effectively undermines the whole basis of the support which the noble Lord has been talking about. Will he give an assurance that the Government will make sure that accurate diagnosis, which can be life-changing, is maintained for this group because it helps through education and throughout life?

Lord Agnew of Oulton

My Lords, the document to which the noble Lord refers recognises that early identification and intervention is important to meet the needs of children and young people with literacy delays. On the necessity of a dyslexia diagnosis, I do not have expertise in such matters. However, the noble Lord and the British Dyslexia Association do, and I would encourage Warwickshire local authority to consider carefully its advice on this point, and on the document generally. I share the noble Lord's frustration that it has not responded to the British Dyslexia Association's letter written over two and a half months ago.

Lord Winston (Lab)

My Lords, I am astonished that the Government do not know the figures for the relative incidence of the spectrum disorders in schools. I declare an interest as a member of staff of Imperial College. Is the Minister aware of our programme where we have managed, hugely successfully, to encourage dyslexic students, in particular, to gain very high educational qualifications? But of course, if the condition cannot be identified, it is very difficult to do that.

Lord Agnew of Oulton

My Lords, I acknowledge the great work the noble Lord, Lord Winston, is doing. I am clear that early diagnosis makes a huge difference; it helps the self-esteem of the child in question, and also enables earlier interventions to take place, helping to establish that child on a strong educational pathway.

Lord Forsyth of Drumlean (Con)

My Lords, does my noble friend accept that dyslexia is an impairment that can result in substantial and adverse long-term effects on an individual and their ability to carry out normal, day-to-day activities, and therefore this report is in complete contrast to the legislation that this House has passed?

Lord Agnew of Oulton

My Lords, it is certainly not helpful that Warwickshire County Council is not engaging with the British Dyslexia Association. Under the Equality Act 2010, a person has a disability,

“if he or she has a physical or mental impairment and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities”.

Lord Watson of Invergowrie (Lab)

My Lords, this is not a party-political issue, and I acknowledge that the Minister made time last week, along with the noble Lords, Lord Addington and Lord Storey, to discuss Warwickshire County Council’s guidance with me. That is why the Minister’s words today are disappointing, because I had understood that he accepted that this was an urgent and serious issue. Warwick County Council’s guidance to parents ignores the science and refuses to recognise that dyslexia is a medical condition. One wonders if, perhaps, it has also advised their residents that the earth is actually flat and that there is no such thing as global warming. With Cambridgeshire County Council and Staffordshire County Council considering aligning themselves with Warwickshire County Council’s position, I think it is important that the

Government set out what action they will take to ensure that this misguided guidance is withdrawn as a matter of urgency.

Lord Agnew of Oulton

My Lords, I share the concern of the noble Lord, Lord Watson, and I have offered to write to Warwickshire County Council to understand why it has not responded to the British Dyslexia Association's very detailed and well-written letter, sent two and a half months ago. As I said, we recognise the issue of dyslexia. Many children and young people who have SEN may have a disability under the Equality Act, and as I said, we strongly believe in early diagnosis and early intervention.

Lord Sterling of Plaistow (Con)

My Lords, my grandson—a splendid little boy—is on the spectrum. Only yesterday, we had a meeting with the Minister on the subject of early identification of this problem. There is no doubt about it: the earlier it can be identified the better for everybody, as it gives children a chance to participate in life in a normal way. What was lacking, as many of us here know, is child psychologists. Without many more child psychologists we do not have the ability to identify problems early, and I hope that the Minister, who I know has huge empathy for this subject, might hasten to add to that voice.

Lord Agnew of Oulton

My Lords, I am not sure whether the noble Lord, Lord Sterling, was referring to dyslexia or autism, but he will be aware that we have increased awareness among all schools, and encouraged teachers to increase their awareness. With the Autism Education Trust, for example, we have rolled out a lot of autism awareness training. We now have 190,000 people trained in autism awareness, which is up from 150,000 in June of last year.

Lord Storey (LD)

My Lords, the Minister will recall that during Children and Families Act, the local offer required local authorities to give information about special needs provision, and that information has to be accurate. Does the Minister not agree that it is not helpful to parents when false information is given out by councils, particularly on this issue of dyslexia? Will the Government clarify whether they fully support the recognition of dyslexia as a disability as defined by the Equality Act 2010?

Lord Agnew of Oulton

My Lords, the Equality Act 2010 provides protection for any person with a condition that meets the Act's definition of disability—that is, a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities. The Act does not, except in a few specific instances, mention by name the conditions that automatically fall within the definition of disability. This is because, in most cases, it is the impact on the person's life that is the qualifying criterion, rather than the condition itself.

Appendix D: Codebook

What are the common features that identify why children who have dyslexia and co-occurring conditions fail to thrive in mainstream school?

Appendix D1- Codebook\\Phase 2 - Generating Initial Codes (Open Coding)

Codebook -Phase 2 – Generating Initial Coding involved deconstructing the data from its original chronology into an initial set of non-hierarchical codes

| Phase 2 - Generating Initial Codes - 52 initial codes developed at phase 2 | Phase 2 - Generating Initial Codes - 52 initial codes developed at phase 2 |
|--|--|
| Q-Teacher-LSA - Reflections about Inclusion as meeting needs of SEND pupils | Q-LSAA-Descriptions of types of children who have the biggest impact on whole class inclusion |
| Q-Teacher-LSA-All Pupils-Types of children who have the biggest impact on whole class school inclusion | Q-LSAA-All-pupils-Personal needs |
| Q-Teacher-LSA-All Pupils-School meeting needs | Q-LSAA-All Pupils-School meeting needs |
| Q-Teacher-LSA-All Pupils-Reflections on rating | Q-LSAA-All Pupils-Reflections on rating |
| Q-Teacher-LSA-All Pupils-Planning 5 years ahead | Q-LSAA-All Pupils-Planning 5 years ahead |
| Q-Teacher-LSA-All Pupils-Personal needs | Q-LSAA-All Pupils-Describe the types of children who have the biggest impact on whole class school inclusion |
| Q-Teacher-LSA - Social and academic needs of children with SEN | Q-LSA Reflections about rate of SEN |
| Q-Teacher-LSA - Reflections on confidence to deliver | Q-LSA - Reflections about inclusion as placement of pupils in class |
| Q-Teacher-LSA - Planning 5 years ahead needs | Q-Gov-social academic needs are of children with SEND at school |
| Q-Teacher-LSA - Personal needs with respect to SEN | Q-Gov-Reflections on rate |
| Q-Teacher-LSA - How well does school meet social academic needs | Q-Gov-Reflections about Inclusion as meeting the social academic needs of pupils with SEND |
| Q-Teacher-LSA - Description of inclusion for meeting needs of SEN | Q-Gov-Planning 5 years ahead |
| Q-Teacher-LSA - children who have the biggest impact on whole class inclusion | Q-Gov-Individual needs |

| Phase 2 - Generating Initial Codes - 52 initial codes developed at phase 2 | Phase 2 - Generating Initial Codes - 52 initial codes developed at phase 2 |
|--|--|
| <p>Q-Teacher-LSA - the main social academic needs in class</p> <p>Q-Teacher - Reflections about inclusion as placement of pupils in class</p> <p>Q-Teacher - Comments about rate of SEN</p> <p>Q-LSSA-Personal needs</p> <p>Q-LSAA-Understanding or description of inclusion for meeting the needs of children who have SEND</p> <p>Q-LSAA-Social academic needs of SEND pupils</p> <p>Q-LSAA-social academic needs are of the children</p> <p>Q-LSAA-Reflections on school meeting the social academic needs of pupils with disabilities</p> <p>Q-LSAA-Reflections on rate</p> <p>Q-LSAA-Reflections on inclusion as the placement of pupils with disabilities in mainstream classrooms</p> <p>Q-LSAA-Planning 5 years ahead</p> <p>Q-Gov-Reflections about Inclusion as the placement of pupils with disabilities in mainstream classrooms</p> | <p>Q-Gov-How well does School meet the social academic needs of pupils with SEND</p> <p>Q-Gov-Description of inclusion for meeting the needs of children who have SEND</p> <p>Q-Gov-All Pupils-School meeting needs</p> <p>Q-Gov-All Pupils-Planning 5 years ahead</p> <p>Q-Gov-All Pupils-Individual needs</p> <p>Q-All-Planning 5 years ahead-Inclusion as creating communities</p> <p>Q-All-Novel aspects of inclusion as community</p> <p>Q-All-Individual needs</p> <p>Q-All-Inclusion as the creation of community-strength of School</p> <p>Q-All-Inclusion as the creation of community-challenge to school</p> <p>Q-All-Inclusion as community-children and others impact</p> |

Appendix D2 - Codebook\\Phase 3 - Searching for Themes (Developing Categories)

Codebook – Phase 3 – Searching for Themes – involved merging, renaming, distilling and clustering related coded into broader categories of codes to reconstruct the data into a framework that makes sense to further the analysis.

| Phase 3 - Searching for Themes (Developing Categories) - 42 categories of codes developed at phase 3 containing 163 codes | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|---|--|------------------|------------------------|
| Knowledge Assets and Knowledge Deficits | The kinds of knowledge relied upon to engage in inclusive practice; and its perceived accessibility either directly referenced or alluded to as a deficit | 5 | 181 |
| SITED | Accounts of elements of SITED. the original explanatory framework developed from the literature Of structure/strategy, Intensity, timeliness, evaluation and delivery | 6 | 113 |
| Concepts of Inclusion | Moral and ethical issues, constructs about inclusion and inclusive practice | 5 | 103 |
| parent identity | The way in which a parent's constructs their identity as competent and able to support and protect their child | 4 | 85 |
| Definition of Special Educational Needs and Disability | How SEN&D is defined in practice and how this may differ from the legal constructs of SEND | 3 | 36 |
| typical development | Accounts and observations about typical development | 4 | 28 |
| value of disability | This node addresses the idea of disability having value to others, as a point of learning or a tool for reflection. The important point about this node is it's not how the individuals with the difficulties or disability see their position is how others value the difficulties. | 1 | 27 |
| Legal Issues | Factors associated with legal aspects of special educational needs, special educational provision or definition of disability. Also includes aspects of provision of support in school | 2 | 27 |
| attributions | Attributions made by parents or professional staff to account for behaviour or consequences | 2 | 26 |
| expectations | A strong belief that orientates self and actions that something will happen or be the case | 6 | 25 |
| The Child | Constructs of the child | 4 | 23 |
| Provision | Commentary about the effectiveness or not of services and support that are part of the management of the child or young person needs. Comes under both quality first teaching and the Special Educational Provision headings. | 4 | 22 |

| Phase 3 - Searching for Themes (Developing Categories) - 42 categories of codes developed at phase 3 containing 163 codes | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|---|---|------------------|------------------------|
| Resistance | Commentary that shows evidence of resistance to information, social constructs and interpretive repertoires that create challenge or disruption to Interpretive repertoires in this context draw from Potter and Wetherall work around discourse | 2 | 21 |
| Time | The passage of time across both the day and year to different development periods and educational phases referencing of features of time and time and attention that indicate significance, challenge or specificity. | 3 | 19 |
| Bullying | Accounts of behaviours which are perceived to be indicative of bullying either physical or psychological in their impact | 2 | 19 |
| Quotes | relevant quotes from data that may capture key points | 2 | 16 |
| Assessment | Process of obtaining information and Evaluation of information and perceptions which may include the taking up of a position on the matter | 2 | 14 |
| Adaptability | the mechanisms by which individuals or groups of individuals constituting systems can meet change, transition, novelty, and challenge. Capacity to overcome setbacks, challenges, and difficulties that are part of everyday academic life (Collie and Martin 2016) | 4 | 14 |
| Levels of inclusion | This node captures evidence around the levels of inclusion that were abstracted from the literature | 1 | 13 |
| Threat, Anxiety and Stress | negative emotional valency and perceived physical and mental challenge | 2 | 12 |
| Teacher constructs of professional identity | Accounts either self-report or observations and comments of teacher professional self-identity | 4 | 11 |
| Confidence | Full trust; belief in the powers, trustworthiness, or reliability of a person or thing: We have every confidence in their ability to succeed. Belief in oneself and one's powers or abilities; self-confidence; self-reliance; assurance: | 2 | 9 |
| Uneven and Even Access to Education | Pattens of access to education which show variability across the year or across teachers or across topics | 2 | 8 |
| Obstruction | Accounts of structural or agency purposeful barriers to action and resolution of the area of difficulty | 3 | 8 |
| Nurture | A growth approach in which a highly supportive stance of encouragement and empowerment takes place. | 2 | 8 |
| Stress response | Accounts of raised anxiety or depressive responses in relation to acute or persistent sense of threat | 2 | 7 |

| Phase 3 - Searching for Themes (Developing Categories) - 42 categories of codes developed at phase 3 containing 163 codes | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|---|---|------------------|------------------------|
| Specific disorders, disabilities, and difficulties | This node captures references to specific categories of diagnosis or behaviours that are problematic and part of the child or class/school profile | 2 | 7 |
| Teacher Mindset from parents or others | Accounts of how parents or others construct individual teacher, groups of teachers or school attitudes towards their children or education. Includes contested mixed views | 2 | 6 |
| Staffing level | This node is about references direct or indirect to staffing levels or child/staff ratios as part of inclusion | 1 | 6 |
| Anger | Emotional and visceral response to perceived or actual threat and/ or damage either personally directly or indirectly | 1 | 5 |
| Malice | The experience of purposeful actions and behaviours designed to cause inconvenience, hurt or harm either physical, psychological, social or financial | 1 | 4 |
| Family and Friends | The features of the family unit both immediate and extended. that may provide both support but also stressors and strains at person and pair and group level. | 1 | 3 |
| Resilience | A psychological state of being able to summon energy, creativity and focus to meet trauma resulting from of acute or chronic stressors and significant difficulty, and to continue with goal direction despite setbacks, with an expectation of potential success | 1 | 2 |
| Survey ii | Positive aspects identified around inclusion from survey | 1 | 1 |
| Survey | Node of material from survey | 1 | 1 |
| Parental Knowledge and engagement | Accounts of parental knowledge or lack of, and account s of their engagement around identification of need and resources | 1 | 1 |
| Grief and Loss | Emotional and physical state of distress or sadness around child experiences or their limitation of future opportunities and aspirations | 1 | 1 |
| Failure | Explanatory frameworks, or discourse including judgments about the causes or consequences of perceived failure to secure age-appropriate skills | 1 | 1 |
| Expectations unrealistic | Aspirations or positions of judgment that are unlikely to be met in the near or far future due to inherent features of the person, structural features or constraints /demands on others. this can be by parents of their child or of the school or by school staff, the school institution of the child and or the parents | 1 | 1 |
| Emotional Valency | The intrinsic attractiveness (positive valence) or aversiveness (negative valence) of an event, object, or situation. However, the term is also used to characterize and | 1 | 1 |

| Phase 3 - Searching for Themes (Developing Categories) - 42 categories of codes developed at phase 3 containing 163 codes | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|---|--|------------------|------------------------|
| Dyslexia | categorize specific emotions which are characterized as positive valanced emotions and negative valanced emotions. | 1 | 1 |
| Boredom | Accounts of child disengagement broadly defined. | 1 | 1 |
| | | | |

Appendix D3 - Codebook\\Phase 4 - Reviewing Themes (Drilling Down)

Codebook – Phase 4 – Reviewing Themes involved breaking down the now reorganised categories into sub-categories to better understand the meanings embedded therein.

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|--|---------------------|------------------------------|
| Need | Accounts, descriptions or discussion around the construct of need. This may be explicit or can be implicit with the expectation that others will understand what that need is. How the constructive need is used references both ontological and epistemological position of the speaker or author. | 7 | 137 |
| Competency | This draws upon the ideas of capacity to meet task demands with effectiveness and efficiency. It means that the outcomes from a task are efficiently delivered without any substantial disruption to the flow of activity will work surrounding the task. From an internal perception of self it is that the task can be carried out without undue levels of stress-demand that are perceived as anxiety inducing. | 22 | 127 |
| Parent Identity - Competence | The way in which parents enact and understand their identity as competent to be able to enable features working towards independence for educational or social domains and to support and protect their child | 20 | 41 |
| Delivery | The skills or expertise in drawing upon lived experience or specialist knowledge for delivering of learning and support that could be understood as being additional to or different from the child's peers. This could be from the school staff members perspective or from the parent's perspective or it could be through specialist support organised by the parent independent of the school | 6 | 26 |
| Aspirations of competency | How parent, child, teacher or other try to secure competency | 5 | 23 |
| Work-load balance | Text that makes reference to perceived conflicting conflicts in the demands being made of the person or child and the challenges that have to be overcome to meet that expectation. this level of demand may come into conflict with the individuals perceived resources to meet the expectations | 4 | 16 |
| Pressure of work-time | Descriptions and discussions of how time pressures or perceptions of tasks to be completed within defined time periods create a sense of pressure and | 4 | 13 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|---|---------------------|------------------------------|
| Readiness to learn | stress/anxiety. This can be found in teacher accounts, or in parental accounts where there are multiple competing demands which may delay outside the individual person's level of agency to moderate About having the skills to enter into a phase of learning, theses could be academic, social, motor, intellectual or cognitive development. | 3 | 6 |
| Labelling, Diagnosis | Discussion and references to matters relating to categorisation either through referencing labelling or diagnosis. This categorisation can be provided by the child themselves, the parent, school staff or others. The labels, diagnosis or categorisation can be contested or can be agreed upon. | 11 | 60 |
| Describing SEN needs | This node captures any description of SEN needs that may have an impact on learning or social inclusion | 4 | 67 |
| Explanatory framework of difficulty | Alternative explanatory frameworks to account for difficulty | 10 | 60 |
| Not labelling | Account of issues arising out of not labelling or diagnosing difficulties | 8 | 23 |
| Identification of labels and difference | Labelling can be an administrative task but it is also referenced by markers of difference such support provided, equipment different ways of doing things. this can lead to self-identification or rejection of help independent of the actual resource offered and it's suitability | 5 | 17 |
| Boundaries of when needs can be met in what context | The definition of SEN has fluid features, and this node describes the questions or features around what can be managed in a mainstream classroom/school | 1 | 8 |
| History of Development for a child | Accounts of developmental history highlighting key presentation and incidents that were perceived to be important markers of emerging difficulties with development | 2 | 6 |
| Features | How dyslexia is described | 2 | 3 |
| Health Needs | Description of the types of health needs and additional accommodations required | 1 | 1 |
| Emotion | Accounts which capture emotional range outside the typical day to day state. These may be states of happiness, distress, pleasure or of anger and maybe contrary or coherent. The state suggests some kind of reaction to the situation that person found themselves in | 9 | 47 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|---|---------------------|------------------------------|
| Emotions | Accounts of emotional experiences | 18 | 74 |
| Emotions of stress and self esteem | Deals with emotions that are about anxiety in trying to do right or pressure, these are emotions that may be associated with challenges to competency, rather than ones of hurt or anger | 4 | 27 |
| Anger | Emotional and visceral response to perceived or actual threat and/ or damage either personally directly or indirectly | 2 | 10 |
| Stress response | Accounts of raised anxiety or depressive responses in relation to acute or persistent sense of threat | 2 | 7 |
| Movement | Pattens or reason for moves in education at phased changes (structural) or selective (agency) | 1 | 4 |
| Grief and Loss | Emotional and physical state of distress or sadness around child experiences or their limitation of future opportunities and aspirations | 2 | 2 |
| Learning and education features of | The features and accounts of both learning, which is a process of acquiring and using knowledge, and education which is a legal construct | 2 | 47 |
| Future Implications and Expectations | Accounts and descriptions of potential future outcomes, social or academic expectations what the impact of current provision, proposed provision for changes in provision. | 8 | 45 |
| Anticipation of challenge | Accounts where there is anticipation of difficulty or challenges ahead | 8 | 47 |
| Work-load balance | Text that makes reference to perceived conflicting conflicts in the demands being made of the person and the challenges that have to be overcome to meet that expectation. this level of demand may come into conflict with the individuals perceived resources to meet the expectations | 2 | 27 |
| Expectations unrealistic | Aspirations or positions of judgment that are unlikely to be met in the near or far future due to inherent features of the person, structural features or constraints /demands on others. this can be by parents of their child or of the school or by school staff, the school institution of the child and or the parents | 1 | 6 |
| Inclusion level4_ Community | Inclusion as creating a sense of community, within this context it is how others and self have expectations of being an active part of communities of relevance to the person or child | 2 | 5 |
| Staff expectations | Captures the way in which staff construct ability or needs of children or groups of children and their projected or immediate expectations of the child or group | 2 | 5 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|---|---------------------|------------------------------|
| Parental expectations hope | Parental accounts of either development or service provision in which they indicate they have positive or typical expectations. | 1 | 3 |
| Attainment and progress | Measures of education that draw upon normative data and measurement. Marker used to make judgment on access to education, but also in the practical world sufficient competency required to engage in employment and progress through training | 5 | 41 |
| Pressure to achieve (failure) | Accounts of challenge or working close to limit in order to achieve benchmark or expectation. | 1 | 8 |
| Expectations unrealistic | Aspirations or positions of judgment that are unlikely to be met in the near or far future due to inherent features of the person, structural features or constraints /demands on others. this can be by parents of their child or of the school or by school staff, the school institution of the child and or the parents | 1 | 5 |
| Mechanism for organisation and judgment | Attainment as means of identifying service delivery and organisation of individuals and groups | 1 | 1 |
| Risk | Description of circumstances or events that capture the child parent all member of staff been placed in a position of risk/threat to their long-term health and well-being. Risk as a perception and as a form of potential threat, all risk in evidence of imminent or current threat to a child's ability to make appropriate progress, access education, long-term outcomes, self-esteem, health and well-being and general psychological state. | 10 | 39 |
| Family | Accounts of family history of dyslexia and wider response and acknowledgement | 14 | 16 |
| Teacher risk | Features of risk for teachers which can include personal risk, health risk short or long term or professional risk real or perceived | 1 | 6 |
| Legal | References or accounts to the legal process, or the legal framework that special educational needs and disabilities is constructed through and operates by. | 6 | 38 |
| Transparency issues | The degree of specificity inherent in the legal construction of education law and the way in which language is used by others in the legal process that gives rise to misleading impressions and difficulties | 4 | 8 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|---|---------------------|------------------------------|
| Accessibility | Ability to gain access to a body of knowledge, and associated custom and practice around legal matters to do with education; that ordinarily is not used by the person or school | 2 | 3 |
| Framework of provision | References the structural features of provision map either formally through application of the Code of Practice (2015), or through Local authority provision and their systems and structures or informally through school systems | 2 | 3 |
| The Law | References to legal principles or obligations in education law and the Code of Practice for SEND | 1 | 1 |
| Time Features and Accessibility | The reference features to do with time as it impacts on ability to access education, respond to indicators of difficulty, or to do activity. Time is a feature of education which has a liner direction forward and this relates to the capacity to maintain parity with progress | 8 | 34 |
| Time of difficulty | The time frames of when parents noticed key areas of difficulty and what brought it to their attention | 9 | 27 |
| Actions identifying difficulty | Accounts of what precipitated awareness of something was wrong or not right with child's education /learning /progress | 13 | 24 |
| Fixed or Flexible Stance | Description highlighting how a fixed or flexible stance by school staff or parents is taken with respect to child's ability, skills and capacity. This links with issues of growth mindset, control and co-production of learning | 7 | 33 |
| Environment | The physical, social, and psychological features of the learning space | 2 | 32 |
| Resilience | A psychological state of being able to summon energy, creativity and focus to meet trauma resulting from of acute or chronic stressors and significant difficulty, and to continue with goal direction despite setbacks, with an expectation of potential success | 2 | 5 |
| Relationships and Connectivity | Discussions and description around the value of relationships by child, parent, school staff or others. The quality of the relationship and the difficulties when they are limited can form part of the description. Alternatively, efforts to help build social networks handle the presence of effective social networks come out of this description | 12 | 30 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|--|---------------------|------------------------------|
| Child relationships | Accounts from parents and school staff around children's relationships with peers, staff, and others both within the school community and outside of it | 4 | 14 |
| Parents' communication with school | Accounts of positive or not communication | 4 | 8 |
| Communication matters school-parent-LA | Matters of communication or obstructions of communication that impact positively or negatively on the fluid management of a child's education | 3 | 5 |
| Positive mindset | Perceptions of positive mindset by teachers towards child, family, friends and education | 2 | 5 |
| Friends as a source of support or knowledge | Friends who have knowledge acting as support, keepers of history and knowledge. the informal network of those that provide the social glue | 2 | 4 |
| Parent social connectivity | Addresses parents' connectivity located around recognition of common experiences | 3 | 3 |
| Negative mindset | Accounts of negative perceptions or responses by teachers about parent or child or family/friends | 2 | 3 |
| Structure of Provision | Descriptions and accounts of structural features around support, providing intervention or managing difference both within and without the classroom. This can be formally established structural organisation within the school, or independently organised additional support outside school setting, or informal strategies that provide some kind of structure within the home | 9 | 27 |
| Difficulties and discontinuities in provision | Accounts of discontinuities in assessment or provision and in review. Gaps occurring in the effective continuities of education | 9 | 142 |
| Structural features education | Descriptions of provision and differences and similarities in settings and expectations | 4 | 52 |
| Staffing level | This node is about references direct or indirect to staffing levels or child/staff ratios as part of inclusion | 2 | 42 |
| Temporal aspects of provision | Aspects of delivering provision that are linked to time. this can be in the development of or delivery or reflection upon provision | 2 | 42 |
| Spatial aspects of provision | How space is part of the construction of provision | 1 | 34 |
| Provision | Commentary about the effectiveness or not of services and support that are part of the management of the child or young person needs. Comes under both quality first teaching and the Special Educational Provision headings. | 3 | 7 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|---|---------------------|------------------------------|
| Knowledge by parent or teacher of structure | The knowledge and understanding of the structural features that given and direct education and particularly education for children with additional learning needs | 3 | 6 |
| Preparing for adulthood | Skills or ways of being that need to be acquired for life after school | 1 | 1 |
| Fairness, Justice | Discussion or description which references constructs of fairness and justice in relation to unequal treatment relative to the peer group who do not have difficulty. Fairness and justice can be constructed both ways, has disadvantage to those with disabilities and difficulty or has more favourable treatment to those with disabilities and difficulty perceived disadvantage to the ordinary students. | 5 | 22 |
| Inclusion as a division of resources | How different resources such as materials types of staff, personal /social resources | 6 | 93 |
| Uneven and Even Access to Education | Pattens of access to education for children with differences or difficulty which show variability across the year or across teachers or across topics | 10 | 73 |
| Application of resources | Accounts of how resources have been applied to enable access to education | 5 | 73 |
| Inclusion as division of time | Allocation of resources in equal units of time or effort as a construct of inclusion | 5 | 26 |
| Lack of fairness | When meeting needs or not meeting them is perceived to lack fairness or justice | 1 | 15 |
| Inclusion | Ideas around or descriptions of inclusion (drawing upon the G&N model | 3 | 9 |
| Power | Description and accounts of imbalances in power and authority by actors within special educational needs and disability framework. These accounts may be over, but they may reflect the consequences when power is used both positively or negatively. Constructed power is both structural and agentic | 7 | 21 |
| Bullying and Malice | Accounts of behaviours which are perceived to be indicative of bullying either physical or psychological in their impact and which are perceived to be about power and threat | 2 | 21 |
| Obstruction and Resistance | Features of agency or structure that create barriers or discontinuities in education access or experience that impact on rapid repair creating | 5 | 21 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|--|---------------------|------------------------------|
| | barriers and frustrations or challenges that required energy to be directed at them | | |
| Resource obstruction | The lack of capacity to meet need or change due to resource limitations | 1 | 47 |
| Inertia | The capacity to have inbuilt resistance to change, a degree of stasis that needs to be overcome. | 1 | 29 |
| Administrative obstruction | When procedures and processes are used or abused to frustrate access to education through the system | 2 | 4 |
| Ability to meet thresholds | Capacity of pupil to be able to meet the entry level requirements | 1 | 4 |
| Service obstruction | Accounts of how an associated service refuses to engage or accept referral. points of service gaps. may link with administrative obstruction | 2 | 3 |
| Resistance to Change | How parents manage the difficulties of finding a school or service is not working effectively for them and their child and conflict and actions that flow from that | 2 | 2 |
| Language use | How language is used to communicate, engage or disengage others through type and nature of communication | 2 | 2 |
| None obstruction | Expectation of not having obstruction or difficulty | 1 | 2 |
| Physical obstruction | Features of the environment frustrate or are direct barrier for effective access to others such as teachers, administrators for parents, or to education such as lack of appropriate equipment | 1 | 1 |
| Psychological obstruction | Attitudes or actions by others that engender a psychological loss of confidence or equilibrium and frustrate access to or passage in the education system | 1 | 1 |
| Explanatory Frameworks | Self-adopted explanations to account for circumstances or observations that provide a machinist account for circumstances. the accounts draw upon a person's knowledge, and as such highlight both knowledge and gaps in knowledge | 4 | 20 |
| Explanatory framework of difficulty | Alternative explanatory frameworks to account for difficulty | 10 | 90 |
| Emotions | Accounts of emotional experiences | 3 | 28 |
| Social World | Accounts of the way in which children and parents organise and enable social worlds for themselves. These accounts may be from the child's parent's perspective from those observing such as schools or others. | 6 | 18 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|--|---------------------|------------------------------|
| Parent identity | The way in which a parent constructs their identity as competent and able to support and protect their child | 2 | 14 |
| Understanding child's social world | Parents or others understanding of social world or barriers to understanding it | 2 | 11 |
| Bullying | Accounts of general or specific incidents where the issue of bullying is raised. | 3 | 4 |
| Support and empowerment children | Ways in which child or children are seen to respond positively to children with differences | 1 | 4 |
| Inclusion | Accounts describing features or aspects of inclusion or the structural features used to support the narrative and actions of inclusion | 10 | 15 |
| Level B | Child in class | 4 | 88 |
| Group size and profile | Features about groups that create difficulty or create opportunity | 3 | 41 |
| Inclusion as a practice | Inclusion as a stance about the person or about the group. covers attitudes, values and ways of being | 4 | 40 |
| Operationalisation of inclusion | How inclusion is practiced in contrast to those they think about it | 4 | 32 |
| Boundaries of Inclusion (Children) | The extent to which individual children's needs can be met without fundamental disturbance of the group or intrusion on the capacity of others to engage in effective education and learning | 4 | 31 |
| Knowledge and skills creating or facilitating inclusion | Types and nature of knowledge or skills or attributes that are used to facilitate or create inclusion for children, groups or setting | 2 | 31 |
| Inclusion as a threat | The ways in which school staff perceive inclusion as source of threat and stress | 2 | 28 |
| Social inclusion v educational inclusion | This node is about how there are different dimensions to inclusion and that social inclusion and educational inclusion are not the same thing. | 4 | 25 |
| Definition of inclusion | How inclusion is defined by participants | 2 | 23 |
| Level D | Creating a sense of community | 3 | 22 |
| Inclusion as process | Inclusion as a continual work in progress and a process rather than a specific target | 4 | 22 |
| Level C | Meeting needs of all in class | 3 | 19 |
| Social learning and discipline | Accounts about how children learn or develop social and prop social behaviours that may inhibit or detract from ability to integrate. Links with executive function capacity | 4 | 19 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|--|---------------------|------------------------------|
| Individual differences | Narratives around different strengths and abilities which may be used as a form of narrative compensation for a child with difficulties | 2 | 19 |
| Level A | Presence of child in class | 5 | 18 |
| Social and psychological inclusion | The markers and accounts of perceptions that an individual child or group are engaged in social /psychological inclusion. | 3 | 18 |
| Care and Caring | The use of Care as a construct of inclusion and/or a mechanism for delivering inclusion | 3 | 18 |
| Inclusion as outcome | The focus of inclusion being on the outcome to be achieved. Inclusion is a goal or target to be achieved. | 4 | 17 |
| Reasons why important | Accounts of how inclusion is perceived to have longer term broadly defined future social impact | 2 | 17 |
| Education inclusiveness | The demands and expectations of the educational school system which children have to meet. the threshold of minimum functionality that the setting requires for education inclusion to operate | 3 | 13 |
| Identity | Features about how identity and sense of self may develop or be challenged | 2 | 13 |
| Factors impacting on inclusion (external) | Accounts of factors external to the school setting that have a bearing on inclusion and its construction in the school | 2 | 12 |
| Inclusion in other places and forms | The different ways in which the practices of inclusion occur outside the school context | 4 | 10 |
| Non inclusion | Accounts of activities or perceptions of attitudes designed to result in non-inclusion, this may include illegal as well as legal activities | 5 | 7 |
| Common-uncommon narrative | The way in which common social narratives and school specific narratives are used to describe inclusion and its practices | 2 | 6 |
| Inclusion as loss | This node explores the ideas of loss that occurred around trying to achieve inclusion. | 1 | 5 |
| Transitions of Inclusion | The way different phases of development are marked by different form of needs with respect to Inclusion | 3 | 5 |
| Finding common cause and social connectedness | This is about how children will seek out others who are situated at similar levels of the social hierarchy | 2 | 4 |
| Social exclusion | These are accounts of how children overtly or covertly were rejected or isolated sufficient for perceptions of exclusion to be constructed | 2 | 4 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|--|---------------------|------------------------------|
| Inclusion | The action or state of including or of being included within a group or structure. | 1 | 1 |
| Gender | The way gendered descriptions are used as attributions, explanations or relevant features | 6 | 13 |
| Technology | Discussions and descriptions of and about how technology is valued or accessed to mediate difficulties in engaging with education both in school and home. This can include a failure to be able to access technology, or the way in which parents seek to overcome obstacles in securing technology support. | 4 | 10 |
| Absence of technology | Account of difficulty when technology should be used but is not being accessed | 3 | 7 |
| SITED | The constructive five key features are effective intervention is derived from the literature. These being structure-strategy/intensity/timeliness/evaluation/delivery. References in the accounts which draw upon these as explanatory frameworks for white is possible or not possible to deliver effective intervention would come under the heading | 5 | 8 |
| Disability as a Resource | Descriptions or accounts of how disability misery source useful for learning and social enhancement for other people. Such accounts focus on the advantage to the others of having a disabled person present, rather than the advantages for the disabled person been placed within the presence of others. | 2 | 8 |
| Value of disability | This node addresses the idea of disability having value to others, as a point of learning or a tool for reflection. The important point about this node is it's not how the individuals with the difficulties or disability see their position, it is how others value the difficulties. | 2 | 49 |
| Developmental Trajectory | Development as a sequential hierarchy of progressively nested skills and abilities that may develop in parallel, or may show uneven pattern of skills which may have typical, relative deficit or relative advantage presentation. The rate of acquisition of skills relative to chronological age or the typical period in which the skills are normally developed to a | 3 | 6 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|--|---|---------------------|------------------------------|
| | | level of mastery forms a reference point for redevelopment which would form trajectory in which a child's development can be notionally compared. | | |
| History of Development for a child | | Accounts of developmental history highlighting key presentation and incidents that were perceived to be important markers of emerging difficulties with development | 9 | 32 |
| Typical development | | Accounts and observations about typical development | 6 | 31 |
| Specific disorders, disabilities, and difficulties | | This node captures references to specific categories of diagnosis or behaviours that are problematic and part of the child or class/school profile | 3 | 24 |
| Development as shown with progress | | The way development is marked and captured by both internal personal relative progress, relative progress to external measures and absolute progress | 5 | 13 |
| Agency | | Descriptions of when individuals acted against various structural features or used the structural features to enhance or enact an outcome. Agency can be demonstrated through activity, creativity, empowerment, or perceptions by self or others of confidence in which change is facilitated. | 3 | 5 |
| Confidence | | Full trust; belief in the powers, trustworthiness, or reliability of a person or thing. Belief in oneself and one's powers or abilities; self-confidence; self-reliance; assurance. This confidence can be misplaced or overrated; alternatively, it can be understated and underrated. This is a state located around the person's view of their capacity to complete the task effectively | 18 | 105 |
| Meeting needs | | Descriptions of activities, approaches, patterns of work or strategies that allow a child to acquire precursor skills or engage with knowledge acquisition and education. This construct is locating deficits and difficulty within the child and draws upon Vygotsky ideas around socio cultural learning | 7 | 45 |
| Nurture as a form of agency | | Accounts of environmental or personal attributes that are perceived to promote inclusion for those at risk. This can include physical, structural and interpersonal features. | 6 | 27 |
| Sourcing help and assessments | | Accounts around actions of mothers or others to secure information, assessment, or explanation of child's profile | 8 | 22 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|---|---------------------|------------------------------|
| Resilience | A psychological state of being able to summon energy, creativity and focus to meet trauma or challenge resulting from acute or chronic stressors and significant difficulty, and to continue with goal direction despite setbacks, with an expectation of potential success | 6 | 15 |
| Lack of agency or constraints on it | Accounts that capture lack of agency or passivity or constraints on agency | 3 | 15 |
| Understanding of the world and identity | How the individual understands their place in the world and their judgments about the world | 3 | 10 |
| Creativity | Capacity to find novel solutions or developing innovative ideas and novel understanding around a problem or task. | 5 | 9 |
| Child agency | Account of children exerting positive or negative agency | 3 | 7 |
| Empowerment | The capacity for an individual to exert agency | 2 | 5 |
| Parental holding to account | Evidence of parental challenge and action on behalf of their child | 1 | 4 |
| Passive or non-agency | Accounts where agency is either denied or not engaged or only partially engaged, and where a passive approach which refers to structure is the dominant feature | 3 | 3 |
| The Child | This is a focus on a specific child in the context of other children, rather than a group of children. the Code of Practice located the issue of SEND at the individual child level. | 1 | 2 |
| Seeing differences and recognition of difficulty or difference | Accounts around differences observed in the child relative to their peer group of typically developing children. This includes accounts of difficulties the specific and general, as well as areas of strength and advanced skills. | 23 | 126 |
| Knowledge of child Need | Accounts of parents, teachers or others awareness of individual need, the importance placed upon recognising individual need, or the contrast of non-individual need, or partial individual need. Accounts can capture where one party has knowledge of the child, which the other party may not have or may resist receiving. The contrast can be between the depth of knowledge and the way that knowledge is enacted | 21 | 56 |
| Presentation of difficulty | Descriptions of the types of difficulty children observed to have | 17 | 40 |
| Negative Mindset | Accounts of negative perceptions or responses by teachers or parent, of others child family/friends or education | 8 | 24 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|--|---------------------|------------------------------|
| Positive Mindset | Perceptions of positive mindset by teachers or parents and others towards child, family, friends, and education | 7 | 20 |
| Parent Identity | The ways and means that parents construct their identity as a mother or father in respect of their roles in relation to their child's education and social well-being. Includes accounts of where the identity gets supported or challenged and the degree to which implicit ideas of personal competence may inform identity | 6 | 20 |
| Behaviour | Account of behaviour which show differences, difficulty and variation from the typical | 4 | 16 |
| Tribes insiders and outsiders | Accounts of comfort in identifying person with similar characteristics, if membership is something that is rejected or embraced | 5 | 15 |
| Finding a tribe | Accounts around finding others who have similar experiences and can share life space and understanding. the importance of people like us | 7 | 12 |
| The child | Constructs of the child | 3 | 10 |
| Knowledge | Understandings of parents, teachers and others. The knowledge can be held private or can be through a variety of mechanisms enacted in a public space either by the questions, the demands, or the ways of responding to a given incident or sequence of situations. | 2 | 2 |
| Technical knowledge access and use | Account of how parents or school staff or schools have accessed and used technical knowledge or technical experts in an area of concern | 9 | 73 |
| Accessibility to knowledge | Accounts of the mechanisms that staff use to gain access to relevant information or the difficulties in gaining access to relevant resources or info. | 7 | 59 |
| Knowledge Assets and Knowledge Deficits | The kinds of knowledge relied upon to engage in inclusive practice; and its perceived accessibility either directly referenced or alluded to as a deficit | 2 | 47 |
| Discontinuities and discrepancies in knowledge | Accounts were the parents or school has a lack of confidence in the account as there is evidence they can access that challenges the account. | 3 | 27 |
| Parental Knowledge and engagement | Descriptions by parents of the knowledge and their understanding of dyslexia, inclusion, education system and its legal framework. This also includes the knowledge around how they identify need and resources to address a child's or theirs needs. It also includes the degree of ease or otherwise in which they can engage the child, the system and the school | 10 | 26 |

| Phase 4 - Reviewing Themes (Coding on) 42 Categories reduced and consolidated into 29 categories supported by 256 codes at phase 4 | Code Definitions for Coding Consistency (rules for inclusion) | Interviews Coded | Units of Meaning Coded |
|--|---|---------------------|------------------------------|
| Knowledge of Dyslexia and Specific Learning Difficulties | Knowledge by school staff and parents of their understanding of the underlying mechanisms, presentation and methods of remediation for Dyslexia-Specific Learning Difficulties. Accounts can represent both inaccurate, partial and sound understanding relative to current knowledge | 10 | 19 |
| Judgment | Accounts of the child, the parent, school staff or others are perceived to have rendered the judgment on them. | 2 | 2 |
| Evaluation | Accounts and discourses which are structured around evaluation of persons and services, also includes explanatory frameworks | 4 | 35 |
| Professional judgment | The assessments teaching staff make about specific children's or groups of children's needs and associated distribution of resources | 8 | 28 |
| Assessment | Process of obtaining information and Evaluation of information and perceptions which may include the taking up of a position on the matter | 2 | 18 |
| Parental judgment | Accounts of where parents have made judgments on others both positive and negative around the behaviour or expectations of them as parents | 4 | 16 |
| Parent perceptions of teacher constructs and identity | Views or judgments of parents about teacher constructs and professional identity | 7 | 16 |
| Teacher assessment | Accounts of teachers transparent or opaque assessment of children by both teachers themselves, Teaching assistants and parents | 5 | 13 |
| Attributions | Attributions made by parents or professional staff to account for behaviour or consequences | 3 | 11 |
| Gaslighting and Invisibility | The denial or disregard of parental reality. observations or information the rendering of invisibility | 5 | 11 |
| Parental assessment of others | The views and judgments of parents about their child, other children, parents the teaching staff, the school, the Local Authority, and others | 8 | 10 |
| Acknowledgement and Recognition | This is the counter point to gaslighting and invisibility. It is about making the child and parents case real though acknowledgment and action and needs recognition | 2 | 6 |
| Child account of judgment | Accounts via parents how child views or constructs judgment of him or others | 2 | 3 |
| Governor assessment | This node is about how those responsible for the school understand need at a group rather than individual level | 1 | 2 |
| | | | |

Appendix D4- Codebook\\Phase 5 - Defining & Naming Themes (Data Reduction)

Codebook – Phase 5 – Defining and Naming Themes involved conceptually mapping and collapsing categories into a broader thematic framework.

| Phase 5 - Defining and Naming Themes - 5 themes identified in Phase 5 with 30 sub-themes | Interviews/ Survey Coded | Units of Meaning coded |
|---|--------------------------|------------------------|
| 1. Structure | 36 | 1808 |
| 1.1 Geographical boundaries | 15 | 380 |
| 1.2 The child | 15 | 105 |
| 1.3 The school culture | 20 | 766 |
| 1.4 The segmentation span of the arc | 27 | 408 |
| 1.5 Legal | 13 | 72 |
| 1.6 Policy and Financial framework | 16 | 77 |
| 2. Visibility | 41 | 7571 |
| 2.1 Learning from a rural primary school - visibility in action | 30 | 2197 |
| 2.1.1 Visibility, and what the focus on the single child can inform | 25 | 439 |
| 2.1.2 Visibility in relation to multiple children | 25 | 439 |
| 2.1.3 Visibility – professional systems | 30 | 471 |
| 2.1.4 The making of visibility - the parent contribution | 26 | 440 |
| 2.1.5 The nature and types of visibility in a rural primary school - a summary | 24 | 408 |
| 2.2 Issues of visibility in schools - the typical account | 39 | 2433 |
| 2.2.1 The constraints of parental skills & and teacher time on creating inclusion | 32 | 482 |
| 2.2.2 Difficulty and debate for visibility and recognition of diagnostic features | 39 | 1734 |
| 2.2.3 Link between skills, formation of inclusion and location of learning | 30 | 217 |
| 2.3 Resources, visibility, and fairness the challenges to delivering inclusion | 23 | 890 |
| 2.4 Invisibility and personal knowledge parent and teacher accounts | 33 | 469 |
| 2.5 The parents' case study account | 30 | 1497 |
| 2.5.1 Visibility of intervention - a focus on the specific child, the impact of interventions | 24 | 413 |

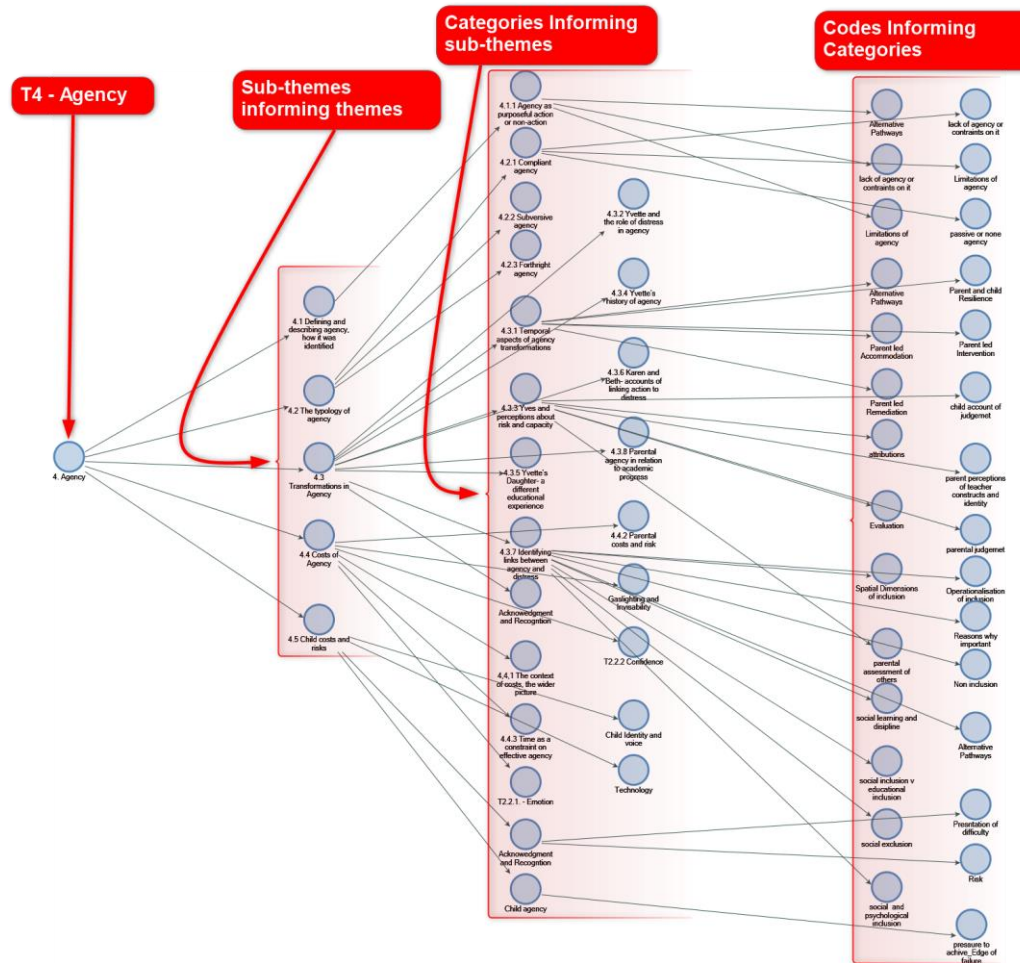
| Phase 5 - Defining and Naming Themes - 5 themes identified in Phase 5 with 30 sub-themes | Interviews/ Survey Coded | Units of Meaning coded |
|---|--------------------------|------------------------|
| 2.5.2 Symptomatic vs specific intervention - accommodation or remediation | 29 | 499 |
| 2.5.3 Failures of visibility in action the case of Karen and Kevin | 25 | 396 |
| 3. Discontinuity and disjuncture | 44 | 8781 |
| 3.1 How are discontinuities and disjuncture understood in this study | 30 | 1742 |
| 3.1.1 Case study - Kevin's science lessons | 24 | 503 |
| 3.1.2 Making sense of Kevin's lesson experiences - abstracting relevant information | 24 | 502 |
| 3.2 Typology | 31 | 527 |
| 3.3 Micro discontinuities and their contribution to disturbances of inclusion | 33 | 349 |
| 3.3.1 The visibility of micro discontinuities | 11 | 160 |
| 3.3.2 The role of cognitive processing - poor attention and memory and links to discontinuity | 13 | 58 |
| 3.3.3 Challenge self-competency | 21 | 129 |
| 3.4 Meso discontinuities | 30 | 2720 |
| 3.4.1 Positive disruption, discontinuity, and disjuncture | 26 | 796 |
| 3.4.2 The problem of non-disruption of trajectory | 23 | 782 |
| 3.4.3 Operating close to the edge of failure-discontinuity and risk | 25 | 973 |
| 3.4.4 Creating visible discontinuity, the problem of intervention | 9 | 169 |
| 3.5 Macro Level - educational failure and opportunity | 40 | 3370 |
| 3.5.1 Positive outcomes from disjuncture | 13 | 77 |
| 3.5.2 Negative outcomes from disjuncture | 11 | 160 |
| 3.5.3 Creating the circumstances of disjuncture | 31 | 2318 |
| 3.5.4 The role of diagnosis and communication in disjuncture | 26 | 528 |
| 3.5.5 Bullying as a form of macro disjuncture | 32 | 287 |
| 4. Agency | 37 | 2443 |
| 4.1 Defining and describing agency, how it was identified | 13 | 68 |
| 4.1.1 Agency as purposeful action or non-action | 13 | 68 |

| Phase 5 - Defining and Naming Themes - 5 themes identified in Phase 5 with 30 sub-themes | Interviews/ Survey Coded | Units of Meaning coded |
|--|--------------------------|------------------------|
| 4.2 The typology of agency | 17 | 177 |
| 4.2.1 Compliant agency | 13 | 48 |
| 4.2.2 Subversive agency | 11 | 63 |
| 4.2.3 Forthright agency | 14 | 66 |
| 4.3 Transformations in Agency | 35 | 1415 |
| 4.3.1 Temporal aspects of agency transformations | 12 | 68 |
| 4.3.2 Yvette and the role of distress in agency | 13 | 104 |
| 4.3.3 Yves and perceptions about risk and capacity | 13 | 94 |
| 4.3.4 Yvette's history of agency | 16 | 186 |
| 4.3.5 Yvette's Daughter- a different educational experience | 16 | 202 |
| 4.3.6 Karen and Beth- accounts of linking action to distress | 28 | 246 |
| 4.3.7 Identifying links between agency and distress | 15 | 215 |
| 4.3.8 Parental agency in relation to academic progress | 16 | 106 |
| 4.4 Costs of Agency | 35 | 507 |
| 4.4.1 The context of costs, the wider picture | 10 | 31 |
| 4.4.2 Parental costs and risk | 11 | 53 |
| 4.4.3 Time as a constraint on effective agency | 2 | 5 |
| 4.5 Child costs and risks | 31 | 276 |
| 5. Inclusion | 44 | 10544 |
| 5.1 School and parents' expectations of universal education & inclusion | 31 | 1670 |
| 5.1.1 Parental perspectives on inclusion | 18 | 734 |
| 5.1.2 Why inclusion fails for children with dyslexia. | 27 | 936 |
| 5.2 The aspiration of inclusion to dissolve disabling environments | 31 | 1369 |
| 5.2.1 The school environment -the social model | 25 | 807 |
| 5.2.2 The social model and child's voice possibilities of futures | 31 | 562 |

| Phase 5 - Defining and Naming Themes - 5 themes identified in Phase 5 with 30 sub-themes | Interviews/ Survey Coded | Units of Meaning coded |
|---|--------------------------|------------------------|
| 5.3 The child's voice through the parent | 12 | 120 |
| 5.3.1 Child voice | 12 | 118 |
| 5.4 The geographical features of inclusion - how the child occupies two worlds | 17 | 512 |
| 5.4.1 Location differences and shared and non-shared space | 15 | 510 |
| 5.5 Core themes of inclusion | 31 | 896 |
| 5.5.1 Circumstances that caused parents to challenge provision offered | 29 | 397 |
| 5.5.2 Parent perceptions of child inner world - other accounts | 30 | 499 |
| 5.6 Summary - suffering playing an outsized role in accounts of dyslexia | 25 | 353 |
| 5.7 Critical realism as a structure to explore inclusion and child voice and identity | 18 | 541 |
| 5.7.1 Summary of the findings applied to the CR framework | 18 | 541 |
| 5.8 The Real level-structural systems that shape outcomes | 17 | 187 |
| 5.9 The Actual level, the contested business of education | 37 | 4896 |
| 5.9.1 The Actual level | 17 | 703 |
| 5.9.2 Individual differences and discontinuity and disjuncture | 31 | 663 |
| 5.9.3 Interaction of the Actual level features the impact of agency on structure. | 18 | 255 |
| 5.9.4 The role of real level in constraining other structural features, application in practice | 15 | 82 |
| 5.9.5 The Empirical level | 36 | 3193 |

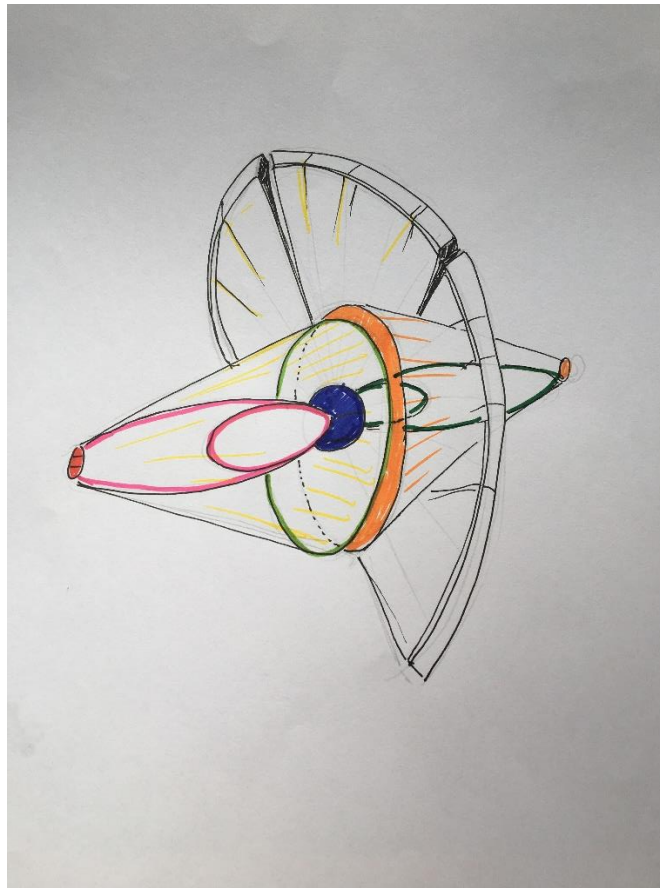
Appendix D5 - Example of flow from codes to categories to themes

Codebook – example of process of conceptually mapping codes to categories to themes for T4 – Agency



Appendix D6- Example of Conceptual Mapping

Codebook – Example of a conceptual map used to make sense of coding and demonstrates processes not easily visible in the codebook, or indeed, the process of coding. Conceptual maps show abstraction, a process that happens in the researcher's head, it further shows the complexity of the topic and the messiness of qualitative analysis.



Appendix D7 - Example of the role Analytical Memo

Codebook – analytical memos were used to conduct a systematic review of the thematic framework developed in phase 5 to analyse, report and ask questions of data. Memo were used to reduce the data from series of nodes to a series of documents explaining outcomes of analysis of nodes. Later, memos themselves were reduced through editing out overlapping and less important content to cohere findings into a cohesive findings chapter.

Phase 6 - Creating the Report - Final themes

| Name | Files | References |
|--|-------|------------|
| 1. Structure | 36 | 1808 |
| 1.1 Geographical boundaries | 15 | 380 |
| 1.2 The child | 15 | 105 |
| 1.3 The school culture | 20 | 766 |
| 1.4 The segmentation span of the arc | 27 | 408 |
| 1.5 Legal | 13 | 72 |
| 1.6 Policy and Financial framework | 16 | 77 |
| 2. Visibility | 41 | 7571 |
| 2.1 Learning from a rural primary school - | 30 | 2197 |
| 2.2 Issues of visibility in schools - the typi | 39 | 2433 |
| 2.3 Resources, visibility, and fairness the c | 23 | 890 |
| 2.4 Invisibility and personal knowledge p | 33 | 469 |
| 2.5 THE PARENTS' CASE STUDY ACCOUN | 30 | 1497 |
| 2.6 Implications for inclusion | 12 | 85 |
| 3. Discontinuity and disjuncture | 44 | 8781 |
| 3.1 How are discontinuities and disjunctu | 30 | 1742 |
| 3.2 Typology | 31 | 527 |
| 3.3 Micro discontinuities and their contrib | 33 | 349 |
| 3.4 Meso discontinuities | 30 | 2720 |
| 3.5 Macro Level - educational failure and | 40 | 3370 |
| Discontinuity Disjuncture | 12 | 73 |
| 4. Agency | 37 | 2260 |
| 4.1 Defining and describing agency, how | 13 | 68 |
| 4.2 The typology of agency | 17 | 177 |
| 4.3 Transformations in Agency | 35 | 1232 |
| 4.4 Costs of Agency | 35 | 507 |
| 4.5 Child costs and risks | 31 | 276 |
| 5. Inclusion | 44 | 10544 |
| 5.1 School and parents' expectations of u | 31 | 1670 |
| 5.2 The aspiration of inclusion to dissolve | 31 | 1369 |

1.1 - The geographical boundaries

Schools had boundaries that are both physical, temporal, and cultural, the latter with its own substructure with governors, head teacher, senior leaders, teachers, and support staff in a hierarchical arrangement. The borders were physical (school gates) and administrative (rules and contact systems) but also had variable permeability. The type of boundary also represented a wider expression of how the school valued the parent and their presence, as Dave's mother Diane's account illustrated:

Well, when he went to [primary school 2] it was absolutely fantastic. The teachers were there at the door at the end of school, at the beginning of school. I could speak to them whenever I wanted to

But the boundary also extended to the act of remote communication as Yves mother Yvette described.

just knowing that they're willing to have a dialogue is massive [...], with primary school they wouldn't even give an email address for us to contact them or anything like that.

Both parents are describing how the geographical boundaries around a school could be used to facilitate or obstruct engagement. Lake and Billingsley (2000) identified how communication was a factor that could lead to escalation or de-escalation of parental conflict as it impacted on parental perceptions. Those barriers around sharing understanding and insights became a leitmotif through the parental data, but also did occur in the school interview data.

In the following extract Frank, an experienced teacher working in a socioeconomically deprived area, reflects upon children's capacity to be the conduit of information and parents'

Codebook – analytical memos were used to conduct a systematic review of the thematic framework developed in phase 5 to analyse, report and ask questions of data. Memo were used to reduce the data from series of nodes to a series of documents explaining outcomes of analysis of nodes. Later, memos themselves were reduced through editing out overlapping and less important content to cohere findings into a cohesive findings chapter.

Appendix D8 - Example of the role of Integrated Annotations

Codebook – example of annotation to integrate contextual factors such as coding assumptions, field notes and observations and researcher's thoughts and ideas during the encoding process

The screenshot displays a text editor window titled "Interview 2_B_vA" with a "Click to edit" button. The main text area contains an interview transcript. A red callout box on the right, with white text, states: "An example of an annotation to integrate contextual factors such as coding assumptions, field notes and observations and researcher's thoughts and ideas during the encoding process". Two red arrows point from this box to specific parts of the transcript: one points to a paragraph describing a child's early life, and the other points to the "Annotations" table at the bottom.

Interview 2_B_vA

Click to edit

I: So, actually what I've gone through, I've gone through the participant's information form with you and so, that was so you're fully informed, you're fine, you've understood the consent, you've understood a little of what I'm going to do and hopefully you fully understood it, that's the other point of consent. And what I'm looking at really, if we start off with, is I'm formally starting the interview now, . I'm wondering if you mind, because all of this is got to be captured for this recording, if you'd mind sharing your memories of his early years, leading up to when he started school.

He came into this world like a bolt of lightning, he...there's a picture in the hall of all the children and seems to be the most alert and aware of the world of those cos you can see it in his eyes. I've commented to him many times, that he was ready for this world, because of his knowledge in those eyes (.) he had a very normal childhood. He walked early, he was toiletied very early, earlier than his brother, who is academically a lot more sound. He spoke at a normal age, physically he was fine, a very expressive child (.) absolutely, you know...the only thing I would say with is when he was born because I tried to stop him being born, he had two blood things on the top of his head...

I: Blisters, like blood blisters?

: Two blood blisters. He had blood blisters because I tried to because he came to quickly. I tried to stop him being born because there was no one else in the room...

I: He's always ahead of the game...

Definitely, yeh and so yeh, no major ...and in comparison as sometimes people, or mothers compare their children, is more advanced in all his goals than was, because was quite a poorly baby and in intensive care and blah, blah, blah, so

| Item | Content |
|------|---|
| 2 | this was an odd interjection into the account and suggests that there remains the possibility that some form of birth trauma may have occurred, or that she perceived that this may have been the case and possibly held herself to account. In respect of this the later contray accounts around development maybe constructed and underpinned by unresolved anxiety around her perceived contribution to the difficulty, ironically the greatest contribution was probably genetic as she had difficulties with writing that suggested some form of dyslexia and there was a marked discrepancy between her keen intelligence and her employment as a |
| 3 | in this extract takes on the voice of both herself and the teacher in a narrative, its clear to the point of being re-lived. what it seems from this account is to be relatively poor adaption by both the teacher and to the situation they found themselves in. Mum's account prior to this was there was no problems but also that he was not ready for school suggesting some kind of problems had been picked up on. the issue of adaption is highlighted by the teachers commenting about there not being a problem. there are two ways of examining this one is that the teacher did not pick up on the problem as she was working around it, |
| 4 | this looks like they were introducing sight recognition of atypical words rather than phonics based approach (circa 2007) |

this is from the start of formal education, indicating that even earlier that he is not making appropriate progress